

**Understanding health beliefs in relation to chronic disease and self-management in a
socio-economically disadvantaged multi-ethnic population**

by

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ABSTRACT

The development of lay-led chronic disease self-management programmes (CDSMPs) is considered to be an effective approach to help people self-manage chronic diseases. Current studies have, in their majority, been conducted with White participants, and it remains unclear whether CDSMPs lead to similar results for other ethnic groups, particularly high risk groups such as South Asians.

This mixed methods research was constructed in two phases. Phase 1 consists of an evaluation of the Chronic Disease Educator (CDE) programme (a lay-led CDSMP). CDEs felt their role often changed during sessions, between a facilitator and educator, and were able to make content culturally applicable. Participants appreciated the group format of the programme. South Asian participants welcomed members of their community delivering the programme in community languages and were much more likely to report gaining new knowledge from attending the programme in comparison to other ethnic groups.

Phase 2 consists of exploring current health beliefs with regards to chronic disease and self-management within the Sikh community. Individuals from the Sikh community accessed a range of systems of support which included traditional health services, alternative remedies, the family and the community, all of which affected lifestyle, disease, symptom and emotional management.

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LIST OF ABBREVIATIONS

A LEVEL	Advanced Level
BCT	Behavioural change theory
BMI	Body mass index
BTEC	Business, Technology and Education Council
CAQDAS	Computer assisted qualitative data analysis software
CDE	Chronic Disease Educator
CDSMP	Chronic disease self-management programme
CENTRAL	Cochrane Central Register of Controlled Trials
CHD	Coronary heart disease
CHW	Community health worker
CI	Confidence interval
CKD	Chronic kidney disease
CLAHRC-BBC	Collaborations for Leadership in Applied Health Research and Care- Birmingham and Black Country
CRD	Centre for Reviews and Dissemination
CVD	Cardiovascular disease
DBP	Diastolic blood pressure
DESMOND	Diabetes education and self-management for ongoing and newly diagnosed (intervention)
DM	Diabetes mellitus
EPP	Expert Patients Programme
ES	Effect sizes

F/U	Follow-up
GNVQ	General National Vocational Qualification
GP	General Practitioner
HbA1c	Glycated haemoglobin
HBM	Health Belief Model
HoBPCT	Heart of Birmingham Primary Care Trust
IQR	Inter-quartile range
LTC	Long term condition
MD	Mean difference
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIHR	National Institute for Health Research
NVQ	National Vocational Qualification
PCT	Primary Care Trust
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised controlled trial
ROMEO	Rethink organisation to improve education and outcomes (intervention)
SBP	Systolic blood pressure
SCT	Social cognitive theory
SD	Standard deviation
SDT	Self determination theory
SF-12	Short Form Questionnaire (12 item)
SF-36	Short Form Questionnaire (36 item)
SMART	Specific, Measurable, Attainable, Relevant, Time sensitive

T1DM	Type 1 diabetes mellitus
T2DM	Type 2 diabetes mellitus
TPB	Theory of planned behaviour
TTM	Transtheoretical model
UK	United Kingdom
US	United States of America
WHO	World Health Organisation
WISE	Whole Systems Informing Self-management Engagement

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CHAPTER 1

1.0 INTRODUCTION

1.1 THE RESEARCH IDEA

Findings from a mixed methods evaluation of the Chronic Disease Educator (CDE) programme (a lay-led chronic disease self-management intervention) and inductive qualitative exploration of health beliefs in the Sikh community (within Birmingham and the Black Country) are presented in this thesis. The research was funded by the National Institute for Health Research (NIHR) through the Collaborations for Leadership in Applied Health Research and Care [Birmingham and Black Country] (CLAHRC-BBC).

1.2 BACKGROUND

The research project was developed because of the growing prevalence of chronic diseases, both nationally and internationally, with the management of chronic diseases placing an increased demand on health resources. Existing literature reports the prevalence of chronic disease is far greater within socio-economically deprived and minority-ethnic populations (Gill *et al.*, 2007; McKeigue and Marmot, 1988; Tudor-Hart, 1971).

The development of lay-led chronic disease self-management programmes (CDSMPs) is considered to be an effective approach to help individuals self-manage their long term conditions (Lorig *et al.*, 1999). Furthermore, the lay-led group-based design of the programme is reported to be cost effective in comparison to one-to-one interventions (Donaldson, 2003). However, evidence regarding the benefits of attending lay-led self-management interventions in the medium to long term is lacking. In addition, current studies of lay-led interventions

have, in their majority, been conducted with mostly White participants; therefore, it remains unclear whether lay-led self-management interventions lead to similar results for other ethnic groups. This is the first evaluation of a lay-led, group-based chronic disease self-management programme delivered to the multi-ethnic population in Birmingham, UK.

The South Asian population in the UK remains a prominent and important area for health research, as they are more likely to suffer from and develop chronic conditions compared to the general population (Balarajan and Bulusu, 1990). However, it must be acknowledged that the South Asian population is heterogeneous and comprised of a number of groups that differ in health beliefs and lifestyle practices (Bhopal and Sengupta-Wiebe, 2000). The Sikh population has some notable differences when compared to their South Asian counterparts (Pakistani and Bangladeshi Muslim); more likely to own their homes, higher levels of educational attainment, and more likely to occupy professional level occupations (ONS Census, 2011). However, the prevalence of chronic disease remains high in the Sikh population and similar to other high risk groups (Gill *et al.*, 2007). Current research with South Asian communities have concentrated on the beliefs and practices of first generation migrants, where little is known about the attitudes of second and third generation participants towards chronic disease self-management and health service delivery.

1.3 STRUCTURE OF THESIS

1.3.1 Phase 1: Evaluation of the Chronic Disease Educator programme

Phase 1 consists of an evaluation of a lay-led chronic disease self-management intervention delivered across inner city Birmingham. The evaluation is theory driven; describing whether

the programme was delivered as intended by programme design. The evaluation involves individuals who delivered the intervention and participants that attended the intervention.

1.3.2 Phase 2: Inductive exploration with the Sikh population

Phase 2 consists of exploring current health beliefs and practices in the Sikh community. Data were collected from Sikh men and women across three generations resident in Birmingham and the Black Country. Participants were questioned on a range of different issues on the topic of self-management identified from Phase 1: perceptions about cause of chronic disease, barriers and facilitators to healthy living, health service provision and emotional well-being. This is the first study to explore health beliefs about chronic disease and self-management across three generations of the Sikh community in the UK.

1.4 BACKGROUND OF RESEARCHER

An important aspect of research is positioning the researcher within the study. I am a researcher with a background in Sociology (BA Hons Sociology, University of Birmingham, 2009) with an interest in using qualitative methods. Born and raised in Birmingham, I feel I can acknowledge and understand many of the different practices present in multi-ethnic, multi-faith, diverse communities. I also consider myself to be both British and Sikh, and can identify with many of my participants with regards to having an identity which is culturally and socially diverse. Nevertheless, my background also raises a number of methodological dilemmas such as, the manner in which to address elders, men and/or women, how to make assumed understandings of cultural issues explicit, and how the style of patient narratives differ in interviews conducted in Punjabi (second language). These issues are discussed further in Chapter 4 (Methodology and Methods).

1.3 RESEARCH DESIGN

A mixed methods approach was adopted throughout this research. These include: interviews (semi-structured), observation (observer as participant), and questionnaires (self-administered). An interpretive epistemological approach was adopted for analysis. The aim was to understand people's experiences of living with chronic disease[s] and attending a CDSMP rather than measuring objective outcomes.

1.6 OUTLINE OF THESIS

Chapter 2 provides an overview of the available literature on chronic disease, self-management and the development of lay-led self-management programmes. Chapter 3 is a systematic review of the effectiveness of lay-led self-management interventions for people with cardiovascular disease and/or diabetes mellitus from minority-ethnic populations residing in high income countries. Chapter 4 describes the methodological approach used in this project and the methods chosen to collect data. Chapter 5 gives a background to the development of the CDE programme and includes demographic information on people accessing the intervention and results from participant self-assessment questionnaires. Chapter 6 presents findings from interviews with lay educators and observations of the CDE programme. Chapter 7 presents findings from interviews with participants who completed the intervention. Chapter 8 provides findings from the inductive exploration of health beliefs in the Sikh community, including how a novel method of interpretation was applied to data analysis. Finally, in Chapter 9 a conclusion to the research is presented, discussing the main results, the strengths and limitations of the data, places findings in the context of British National Health Service (NHS) policy and provides recommendations for further research.

CHAPTER 2

2.0 BACKGROUND

2.1 INTRODUCTION

In this chapter I provide a critical review of chronic disease self-management literature, discussing what the terms chronic disease and self-management mean, and analysing the different behavioural change theories that have been developed to understand and modify human behaviour.

The chapter begins by outlining the context of the research question under investigation, in particular the history and prevalence of chronic disease amongst socio-economically disadvantaged minority-ethnic groups. As the study also inductively explores beliefs and practices in the Sikh community, there will also be an analysis of the prevalence of chronic disease within the South Asian population residing in the UK. A description of past behavioural change interventions delivered in the UK is presented. In addition, there is a discussion on the work of theorists such as Michel Foucault, to assist readers in understanding my interpretative perspective.

The chapter concludes with a summary of the literature, highlighting the key points, limitations and identifying gaps for further research. In Chapter 3 a systematic review of the effectiveness of lay-led group-based chronic disease self-management interventions for minority-ethnic populations in high income countries is presented. I begin this chapter by detailing the context in which the research project was developed, explaining what the

Collaborations for Leadership in Applied Health Research and Care (CLAHRC) is, and the subsequent need for my research to be conducted.

2.2 COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH RESEARCH AND CARE: THE BIRMINGHAM AND BLACK COUNTRY COLLABORATION

2.2.1 What is CLAHRC and what are its aims?

The Collaborations for Leadership in Applied Health Research and Care (CLAHRC) was established in October 2008 by the National Institute of Health Research (NIHR) (www.nihr.ac.uk). Nine pilot CLAHRCs were set up across England to undertake applied health research and support the transfer of research evidence into everyday practice. The nine themes that make CLAHRC Birmingham and Black Country follow a ‘Service Development Laboratory’ model to evaluate service interventions prospectively with formative evaluations (information that is intermittently fed back to service managers to develop or create new services) and summative assessments (evaluations taken over a longer time that will influence the development of services in the future).

There are six core aims of CLAHRC Birmingham and Black Country (CLAHRC BBC 2nd Annual Report, 2011: 8):

- to assess if changes to NHS services work, where, for whom and at what cost
- to develop cross-cutting research topics to enrich evaluations
- to encourage and support sustainable research activity in partnership with NHS organisations in our region and beyond

- to build upon existing relationships between academics, NHS staff, patients and the public
- to build a cohesive knowledge management function
- to create and build international collaborations

2.2.2 CLAHRC Birmingham and Black Country Area

Before the reorganisation of Primary Care Trusts (PCTs) in 2012, CLAHRC-BBC was working in collaboration with all PCTs in Birmingham and two out of four PCTs in the Black Country.

Figure 1: CLAHRC Birmingham and Black Country



Source: Collaborations for Leadership and Applied Health Research and Care (CLAHRC) for Birmingham and Black Country website- Accessed 4th October 2011)

2.2.3 Theme 6- Investment in Prevention (Evaluation of targeted prevention of cardiovascular disease in primary care)

This research project is part of Theme 6- CLAHRC-BBC that aims to address inequalities of cardiovascular health and healthcare in disadvantaged and multi-ethnic communities via two main strands:

1. Evaluation of targeted case finding to identify and manage individuals at high risk of cardiovascular disease (CVD)
2. Evaluation of lay-led self-management interventions for behavioural change and to improve access to healthcare

This research project comprised of the evaluation of the Chronic Disease Educator (CDE) programme forms part of the second strand; evaluating a lay-led group-based chronic disease behavioural change intervention delivered across the former Heart of Birmingham Primary Care Trust (HoBPCT). The project involved close collaboration with commissioners and service managers working at HoBPCT with quarterly steering group meetings updating commissioners on the progress of the evaluation and feeding back initial results. The study also involved working in partnership with a community interest company, Health Exchange, who were commissioned by HoBPCT to deliver the CDE programme. Working in partnership involved attending team meetings with lay educators, the CDE programme manager and support staff. Attempts were made to share information with regards to the evaluation and resolve issues lay educators were facing when delivering the intervention.

2.2.4 Placing research into practice

A key objective of this study was to understand whether lay-led group-based chronic disease self-management programmes (CDSMPs) are a suitable model of service provision for people living with chronic diseases, particularly in socio-economically disadvantaged and multi-ethnic populations. As the CDE programme has been culturally adapted for multi-ethnic socio-economically disadvantaged communities, this research endeavours to establish what culturally modified components of CDSMPs are likely to lead to behavioural changes and help people better self-manage their chronic diseases. Furthermore, the inductive exploration of health beliefs develops a greater understanding of beliefs and practices in the Sikh community with regards to living with chronic diseases and their attitudes towards current NHS services. This greater understanding can inform healthcare policy on how services can be delivered in a culturally competent manner that may be applicable to other populations.

2.2.5 Research Population: Heart of Birmingham Primary Care Trust area

The former HoBPCT area has a diverse multi-ethnic population with seven out of ten residents who are either Black or part of a minority-ethnic group (Heart of Birmingham Primary Care Trust Public Health Report, 2009/2010). The area has the largest Black and minority-ethnic (BME) population (171 000 people, with 55 000 of Pakistani origin [largest BME group]) in comparison to all other PCTs in the country. The population served by HoBPCT is disproportionately young, with approximately a third of the population aged 19 years or younger.

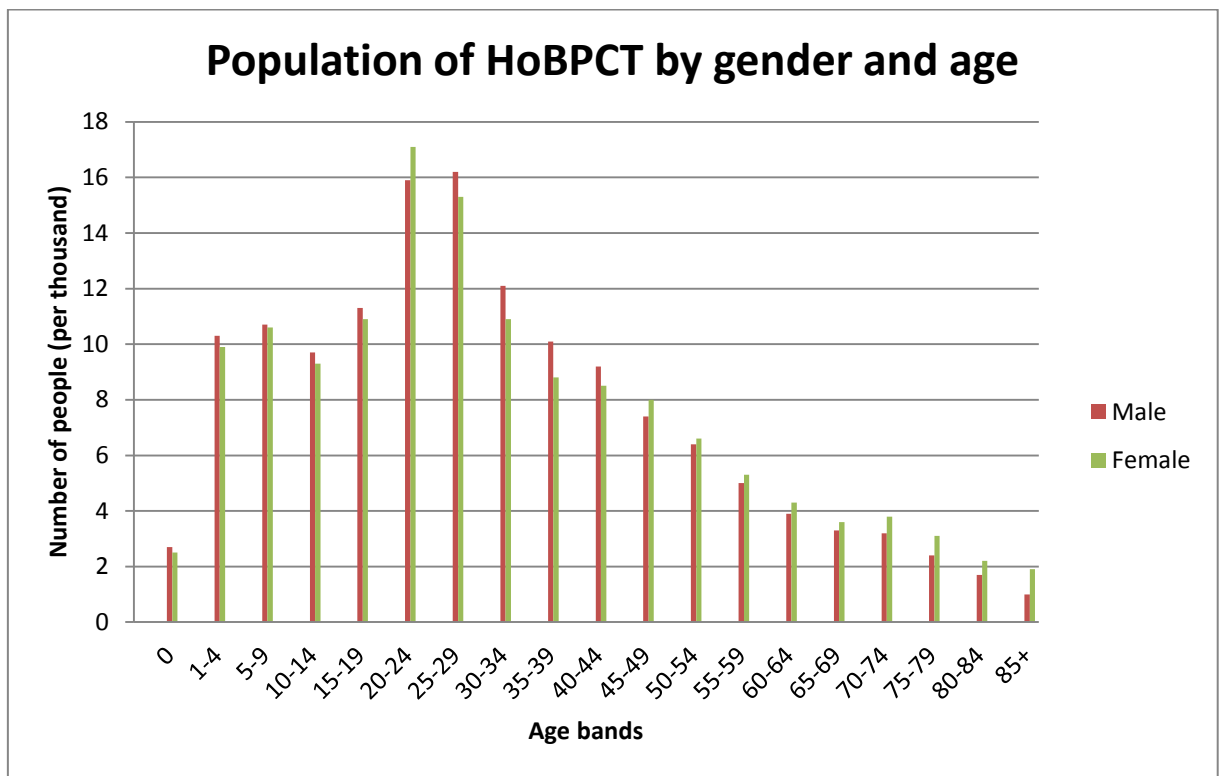
The region is based in the centre of Birmingham and provides healthcare services to 300 000 people throughout the wards of Aston, Handsworth Wood, Ladywood, Lozells & East

Handsworth, Nechells, Oscott, Perry Barr, Soho, Sparkbrook and Springfield (Heart of Birmingham Primary Care Trust Public Health Report 2009/2010). 69% of households in the area are made of large Asian families who mostly live in terraced, rented or semi-detached housing, have no car and who are employed as semi-skilled or unskilled workers (Birmingham City Council-Experian, 2009).

According to the Census (2001) there were 28 592 (2.9%) people resident in Birmingham who described themselves as Sikh, with 57.1% born in the UK, followed by 36.3% born in India. The majority of Sikhs live in six wards, four of which come under the HoBPCT area (Handsworth Wood, Soho, Lozells and East Handsworth, Springfield). Just less than 60% of Sikhs are aged 34 years or less, this compares to 21.6% for the general population. 82.2% of Sikhs resident in Birmingham were owner-occupiers, the highest for any religious group residing in Birmingham.

According to Quality and Outcomes Framework (QOF) for April 2010- March 2011, data for HoBPCT (74 practices, with 321 456 patients registered) showed the prevalence of CHD was 2.3%, 11.1% for hypertension, 6.5% for diabetes, 1.0% for CVD (new diagnosis of hypertension) and 2.5% for CKD. Nationally, the prevalence of CHD is 3.4%, 13.5% for hypertension, 5.5% for diabetes, 1.2% for CVD (new diagnosis of hypertension) and 4.3% for CKD. Figure 2 illustrates the population of HoBPCT by gender and age.

Figure 2: Population of HoBPCT by gender and age



Source: Office for National Statistics (2010)

2.2.5.1 The 'deadly trio' programme

The 'deadly trio' programme was started by HoBPCT in 2007/2008 to tackle the ever-increasing prevalence of coronary heart disease, diabetes and chronic kidney disease; the programme had two clear aims:

- to improve the management of patients already known to have vascular disease- i.e. diabetes, heart disease, and chronic kidney disease
- to identify and treat persons at high risk of developing vascular disease

The programme wished to identify missing patients who were at risk and should be on disease registers. A recent paper by Lambert *et al.* (2011), undertaking the ‘deadly trio’ programme, identified one population who would benefit from cardiovascular health checks; men over the age of 40 living in deprived areas and from minority-ethnic groups. 58 practices and 5871 male participants were included in the analysis. The men eligible for screening had a mean age of 52 years, and South Asians accounted for more than half the sample (Lambert *et al.*, 2011: 2-3). The paper reported that the programme successfully targeted men from minority-ethnic groups, with 705 men added to disease registers. The study highlights that there are a number of patients residing in HoBPCT that could have long-term conditions, therefore the prevalence of chronic diseases such as diabetes, CHD and CKD could be potentially higher than that reported in the Quality and Outcomes Framework database.

2.3 OVERVIEW: WHAT IS CHRONIC DISEASE SELF-MANAGEMENT?

2.3.1 Background

According to the NHS Alliance (2004) chronic disease management is:

A system of coordinated healthcare interventions and communications for populations with long term conditions in which patient self-care is significant (NHS Alliance, 2004: 1).

The Department of Health (2010) define long term conditions (or chronic conditions) as diseases that cannot be cured but can be treated with medication. Throughout this thesis, chronic disease, chronic conditions and long-term conditions will be used interchangeably. Examples of chronic diseases include diabetes, CVD, CHD, asthma and respiratory disease

(Department of Health, 2004). Newbould *et al.* (2006) argue that the focus of self-management should be on helping people living with a chronic disease to develop the necessary skills and confidence to improve the way they manage their illness. However, self-management not only involves managing a chronic disease but also maintaining a level of normality; controlling symptoms, preventing or living with social isolation and maintaining a certain level of well-being (Strauss, 1973).

The notion of well-being is closely associated with the concept of health, defined by the World Health Organisation (WHO, 1946) in a positive manner as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’. The *Ottawa Charter for Health Promotion* (WHO, 1986) built upon this definition where healthy living is the responsibility of the state, the community as well as the individual.

2.3.2 Individual responsibility

Following the *Ottawa Charter for Health Promotion* (WHO, 1986) and changing economic and political circumstances, policy makers and health professionals have developed behavioural change interventions (based on the delivery of health education) to cope with the growing prevalence of chronic disease. Health education is thought to play an important role in empowering individuals and communities to build mutually responsible and supportive networks and to take control over their health. Yet, some have criticised this method because the individual is responsible for identifying and implementing behavioural changes, ignoring environmental and social factors that may act as barriers or facilitators to behavioural change (Weare, 2002).

The concept of responsibility is also identified by Lorig and Holman (2003), who describe self-management as a person's responsibility for their day-to-day management e.g. being physically active or living with a chronic disease. Hence, self-management is based on a notion of responsibility, whereby the individual living with a chronic disease is perceived to have the ability to change their current practices and adopt healthier behaviours. This assumes that each individual has the ability to understand their current social situation (i.e. recognise factors that influence behaviour that they are in control of [direct] and not in control of [indirect]), how decisions relating to chronic disease self-management are made within a wider social context, and have the ability to make appropriate decisions that will lead to an improvement in their quality of life (D'Zurilla, 1987).

2.3.3 Patient involvement in care

2.3.3.1 Shared decision making

The birth of CDSMPs was an attempt by policy makers to increase patient involvement in healthcare, as knowledgeable patients would be able to make better informed health care decisions (Coulter, 1999). Studies with patients living with chronic illnesses have shown that patients often feel left out of health care decisions, citing consultations that are rushed and not empathetic of their emotional needs (Lupton, 1997).

Recently, there has been great discussion with regards to the type of relationship patients want with health care professionals. Critics have condemned the traditional paternalistic doctor-patient relationship as it fails to recognise that patients are experts too (Tudor-Hart, 1988). In an alternative model, the doctor is an expert with regards to meeting the patient's medical needs by providing diagnosis and treatment options, where the patient is considered to be the

only person who understands their experiences of living with a condition and subsequently how to manage symptoms and complications (Greenhalgh and Wessely, 2004).

The call for greater patient involvement is also based on changing political rhetoric as the notion of consumerism is infiltrating health policies in many western countries, particularly the UK. Consumerism has placed a great emphasis on reciprocal responsibility, with patients having greater expectations of the service they receive from health professionals, and patients being responsible for their own behaviour (Coulter, 1999).

Conversely, patients vary in relation to how much involvement they desire in health-care decisions. Most notably, younger participants are more likely to be critical of traditional paternalistic relationships with health care professionals and expect to have active participation within consultations (Coulter, 1994). Older participants living with chronic diseases tend to prefer to place decision-making responsibility with health care professionals, avoiding the possibility of making ‘wrong’ decisions over their health (Charles *et al.*, 1998).

2.3.3.2 Patient-centeredness

Much debate on shared decision making is based on the patient being at the centre of the decision-making process (Stewart, 1995), but patients are not always knowledgeable enough to make ‘informed’ decisions (Elwyn *et al.*, 2000). A feature of patient-centeredness is the steps taken by both the patient and health professional in decision-making: information sharing, making a treatment decision and the need for both groups to agree.

Towle (1997) suggests that a number of prerequisites should be part of the consultation and subsequent decision-making process that occurs between patients and healthcare professionals. Health professionals need to ensure that patients understand the technical aspects of health information and make it known to the patient that they will be involved in the decision-making process. However, findings from Elwyn *et al.* (2000), on a study regarding GP attitudes towards shared decision-making, found there was a need to distinguish whether patients want to be involved in decision making before providing an actual decision-making experience. Stewart *et al.* (1995) counters this argument by citing that a patient-centred approach does not mean patients and health professionals share all information and all decisions, and continues to state that shared decision-making not only occurs in GP-patient consultations but every doctor-patient encounter.

2.4 PREVALENCE OF CHRONIC DISEASE WITHIN THE UK

2.4.1 National prevalence of chronic diseases

There remains some debate when defining chronic disease, but it is generally understood as a disease that persists for a significant length of time, may be progressive and rarely cured (Department of Health, 2004). There is no conclusive list of long-term conditions or chronic diseases; therefore, I will concentrate on the most prevalent chronic diseases internationally: coronary heart disease and diabetes mellitus.

2.4.1.1 Coronary heart disease

In the UK, coronary heart disease (CHD) is the cause of the greatest number of deaths for men and women (British Heart Foundation, 2010). According to the British Heart Foundation (2010), in 2008 over 191 000 people died from heart and circulatory disease in the UK, with

88 000 deaths caused by CHD. One in four deaths in men and one in five deaths in women before the age of 75 are from cardiovascular disease (CVD) (British Heart Foundation, 2010). A recent report from the British Heart Foundation (2011) identified a decreasing trend of mortality rates from CHD in the UK; as in 1961 there were around 166 000 deaths from CHD, but in 2009 this had lowered to 80 000 deaths. Mortality rates from CVD are closely linked to age and gender, as CVD accounted for a third of all deaths in men and women in 2009 and is second only to cancer as the cause of death in every age group younger than 75 (British Heart Foundation, 2011).

Whilst CHD is a major cause of premature death in the UK, there are significant differences in death rates between ethnic groups, by socio-economic status, as well as regional areas. For instance, death rates from CHD are highest in Scotland and the North of England, and the lowest in the South of England (British Heart Foundation, 2010). People of South Asian origin have a 40-50% greater chance of mortality from CHD compared to the White population (British Heart Foundation, 2004). However, as previously stated, death rates from CHD in this sub-group have been steadily falling since 1971 but at a slower rate compared to the White population in the UK (British Heart Foundation, 2005). As a percentage of the total South Asian population within the UK, the prevalence of CHD is highest in Indian (6%) and Pakistani (8%) men. The British Heart Foundation (2005) found the highest mortality rate was with the White population, as South Asian and Black people died more commonly from stroke. For age standardised death rates per 100 000 for people aged 75 or under, South Asian men were as likely to die from CHD compared to White men, but South Asian women were twice as likely to die from CHD compared to White women, and almost four times more likely compared to Black women (British Heart Foundation, 2010).

2.4.1.2 *Diabetes mellitus*

WHO (2011) defines diabetes as:

a chronic disease that occurs either when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces

There are two main types of diabetes: Type 1 (when the body cannot produce any insulin) and Type 2 (when the body is able to make some insulin but it is unable to work effectively, known as insulin resistance) (Diabetes UK, 2012). The estimated global prevalence of diabetes for 2010 was 285 million, with the greatest prevalence in India, China, United States, Russia and Brazil (International Diabetes Federation, 2009), with low and middle income countries facing increasing levels of this disease amongst their populations. The increased risk of diabetes is closely associated with levels of deprivation, as deprived populations are perceived to practice a greater number of unhealthy behaviours, such as physical inactivity and a poor diet leading to obesity (Zanotto *et al.*, 2008).

Unsurprisingly, the most deprived people in the UK are two and half times more likely to suffer from diabetes, with the prevalence greater among men and women with low incomes (Health Survey for England, 2004). Diabetes UK (2012) believes that although 2.9 million people had been diagnosed with diabetes in 2011 there may be an estimated 850 000 who are undiagnosed. The prevalence of diabetes does vary according to ethnicity. Type 2 diabetes is six times more common in people of South Asian descent, and three times more common in people of African and African-Caribbean descent compared to the White population (Diabetes UK, 2012; Department of Health, 2001).

2.4.2 Socio-economic disadvantage and health

The risk of developing and living with long-term chronic diseases is associated with levels of deprivation. Robinson *et al.* (2004) measured the relationship between social deprivation and mortality in adults with diabetes. They concluded that mortality rates were higher with adults from a lower social class compared to adults from a higher social class, higher for adults who had left school before the age of 16 and higher for people that were unemployed at the time the study was undertaken. The study identified unemployment as the most accurate signifier for predicting mortality amongst participants.

The Marmot Review (2010) (also known as *Fair Society Healthy Lives*) outlined a number of key policy objectives to tackle health inequalities. The report recognised that having insufficient money to lead a healthy life can be a significant cause of health inequalities, where there is often a significant difference between the minimum income required for healthy living and the amount of state benefits paid to various groups e.g. unemployed. There is also a considerable importance placed on communities, in terms of physical environment and as a collective group of individuals. The report concludes that people's participation in their communities can help them to gain greater control over their lives and subsequently enhance their psychosocial well-being (Marmot *et al.*, 2010).

Nonetheless, the Marmot Review (Marmot *et al.*, 2010) makes similar recommendations to those in previous reports aimed at addressing health inequalities i.e. Acheson Report (Acheson, 1998). Smith *et al.* (2009) state the government response to tackling health inequalities often begins with a broad recognition of wider determinants of health (income, poverty, employment, environment), but through the course of policy implementation the

focus is placed largely on addressing individual lifestyle factors. Pickett and Dorling (2010) feel that the focus of tackling health inequalities should not be placed solely on the 'poor', as curtailing top incomes would lead to greater redistribution of wealth in society. Pickett and Dorling (2010) continue by criticising the Marmot Review (2010) as the objectives presented were almost identical to objectives of the Black Report (1980; 1992). As a result, they argue that the UK government may frequently implement health policies, but health inequalities show no sign of decline.

2.4.3 Chronic diseases in the South Asian community

The South Asian community in the UK is a heterogeneous population comprised of migrant and British-born Indian, Pakistani and Bangladeshi people. There have been many reasons put forward to explain the high rates of mortality from CHD and diabetes within the South Asian community, ranging from lifestyle to genetic risk factors. A review by Zaman and Bhopal (2012) searched the literature to re-examine risk factors associated with the high rate of CHD in South Asian people in the UK. The review found that recent studies contradict earlier assumptions; the outcome after presentation of CHD is not worse in South Asian people despite the prevalence of diabetes (Zaman and Bhopal, 2012). Insulin resistance is the most prominent genetic explanation for high rates of CHD amongst South Asians (Bhopal *et al.*, 1999). However, there have been no studies, with sufficient power, which prospectively examine the relationship between the South Asian metabolism and coronary outcomes (Ranganathan and Bhopal, 2006).

Bhopal (2000; Rankin and Bhopal, 2001) identified that cultural factors were linked to a high risk of CHD such as smoking, high fat diets and low rates of physical exercise. Research

conducted in South Asian populations has found a diverse range of beliefs and practices relating to specific sub-groups. There are notable differences in lifestyle behaviours amongst Pakistani, Bangladeshi and Indian sub-groups, with regards to smoking patterns, cooking practices (specifically the use of ghee and cooking oils) and the importance of having a physically active lifestyle (Ahmed, 1999; Bhopal *et al.*, 2002; Farooqi *et al.*, 2000; Nazroo, 1997).

According to the British Heart Foundation (2010) the prevalence of doctor diagnosed diabetes (type 1 and type 2) is higher in Black Caribbean, Indian, Pakistani and Bangladeshi men in comparison to the general population (10%, 10%, 8% and 7% respectively and 4% in the general population). Pakistani women are five times more likely, and Indian women two and a half times more likely to suffer from diabetes compared to the general population (Department of Health, 2007).

Physical inactivity is a risk factor for coronary heart disease and diabetes mellitus, as well as other conditions such as stroke and obesity. The Health Survey for England (2000) found that physical activity (i.e. participation in sports and recreational activity) was highest among the White population and lowest among the Bangladeshi population. Studies conducted with South Asian children have shown them to be less active than European children (Bettioli *et al.*, 1999; Fischbacher *et al.*, 2004). Some reasons cited by South Asian communities for low levels of physical activity are insufficient time, lack of single-sex facilities and fear of going out alone (Lawton *et al.*, 2007), although these reasons are much more common in Pakistani and Bangladeshi communities (Bush *et al.*, 2001; Choudhury *et al.*, 2009; Sriskantharajah *et al.*, 2007).

Recently, a small number of studies are beginning to examine whether the children of first-generation South Asian migrants are at equal risk of developing chronic diseases to their parents. Harding *et al.* (2008) found that South Asian adolescents were more likely than White majority groups to engage in poor dietary behaviours. Zaman and Bhopal (2012) conclude that UK-born South Asian children have a high susceptibility of developing chronic diseases due to their affluent lifestyle combined with CVD risk factors from birth. Johnson (2000) concludes that there are subtle differences present in minority-ethnic communities with regards to barriers to physical activity relating to religion, gender or generation and a ‘colour-blind’ approach to tackle inactivity may be counterproductive.

2.5 THE ROLE OF BEHAVIOURAL CHANGE THEORIES

2.5.1 What behavioural change theories are used in health interventions?

Behavioural change theories (BCTs) attempt to encourage a person or community to adopt healthier behaviours and make informed choices regarding their health (Abraham and Michie, 2008). These theories stem from the field of psychology and as a result concentrate on an individual’s intention to change their behaviour. BCTs have been widely used in self-management interventions to encourage behaviour change. BCTs encompass various behaviour change models, such as the Health Belief Model, Social Cognitive Theory, Theory of Planned Behaviour, Self-Determination Theory and the Transtheoretical Model. A brief definition of these theories will now be described and critiqued with their key components cited in Table 1.

The Health Belief Model (HBM) is a theoretical model detailed in *Public Participation in Medical Screening Programs: A Sociopsychological Study* (Hochbaum, 1958). The HBM is

founded upon a structure that is orientated towards achieving a particular health outcome, where the action is dependent on the individual building or having a concern for their health, recognising the perceived threat of being susceptible to an illness and the belief that a particular action can be taken that would decrease the risk of developing the perceived illness (Rosenstock *et al.*, 1988: 177).

The HBM has the benefit of producing a tailored action plan of change through a cost benefit analysis of social, economic and cultural factors that may influence an individual's behaviour. The role of self-efficacy within the individual and their competence to meet goals related to their health are affected by an individual's perception of self; therefore, the HBM model can only be predictive of an individual's ability to change (Abraham *et al.*, 1998). As a result, the HBM model is more of a descriptive model which states the stage an individual may be at with regards to changing behaviour rather than depicting and identifying how change may be encouraged.

Social Cognitive Theory (SCT) (Bandura, 1977) specifies factors that influence behaviours that either reinforce psychological perceptions to change or raise individual expectancies to achieve a desired outcome. Human agency is central to SCT as it provides the individual with the capacity to take control of their quality of life through self-regulation, self-reflectiveness and the belief in achieving a desired outcome (Bandura, 2001). Nonetheless, SCT places a heavy emphasis on the individual to change the necessary characteristics of his/her ill health, as the individual can be blamed if appropriate behavioural changes are not put into action.

The Theory of Planned Behaviour (TPB) (Ajzen, 1980; 1985; 1991) aims to uncover how intentions to perform certain behaviours can be predicted through understanding an individual's attitude toward the behaviour, their subjective norms and perceived behavioural control (Ajzen, 1991: 179). The advantage of this model is how it supports individuals on health programmes by building on personal values that are considered intrinsically valuable. The model is reliant on participants providing truthful accounts of their beliefs and perceptions; if they do not it could lead to a potential waste of time and resources.

Self Determination Theory (SDT) is an approach that attempts to highlight the role of personality development and behavioural self-regulation upon an individual's intrinsic motivation, social development and well-being (Ryan and Deci, 2000). The intrinsic and extrinsic motivational factors in SDT are not time and context bound, therefore, the successful adoption of this theory in programmes is difficult to measure due to time constraints. The theory does centrally focus on the individual and attempts to enhance autonomy from within the person. According to SDT, the individual has a need to be autonomous and connected with others, whereby SDT promotes autonomy-supportive interactions with significant others creating self determined reasons for changing behaviours (Jolly *et al.*, 2009: 176).

The Transtheoretical Model (TTM) uses various stages of change to incorporate different theories from different models (Prochaska and DiClemente, 1984). The model is comprised of six stages: pre-contemplation, contemplation, preparation, action, maintenance and termination. Although the stages are theoretically clearly defined it is still difficult to determine where an individual fits with regards to a particular stage of the model, as the decision-making process can differ from person to person. In addition, assessments of

personal behaviour are often related to perceptions of self and how capable an individual feels they are able to develop new skills.

Table 1. Behavioural change theories and their key components

Theory	Brief Outline	Key Components
Health Belief Model (HBM)	<p>HBM aims to predict whether individuals will choose to engage in the adoption of healthier behaviours to reduce or prevent the chance of developing a disease/ health problem. There are three factors:</p> <ol style="list-style-type: none"> 1. The existence of sufficient motivation (or health concern) to make health issues relevant 2. The belief that one is susceptible (vulnerable) to a serious health problem (this is often termed perceived threat) 3. The belief that following a certain health recommendation/ advice would lead to a reduction in perceived threat that may involve tackling perceived barriers 	<ol style="list-style-type: none"> 1. Perceived susceptibility (the risk of getting a condition) 2. Perceived severity (the seriousness of the condition and its potential consequences) 3. Perceived barriers/ Perceived costs (factors that prevent the individual from adopting the recommended behaviour) 4. Perceived benefits (the positive consequences of adopting the recommended behaviour)
Theory of Planned Behaviour (TPB)	<p>TPB is an extension of the theory of reasoned action (Ajzen and Fishbein, 1980; Fishbein and Ajzen, 1975). A central feature of the TPB is the individual's intention to perform a given action. As a general rule the stronger the intention to perform behaviour the more likely the behaviour will actually be performed.</p>	<ol style="list-style-type: none"> 1. Attitude (Behavioural belief- an individual's belief about the outcomes of a given behaviour; Attitude towards behaviour- an individual's evaluation on the outcome of performing a particular behaviour) 2. Subjective norm (Normative belief- an individual's perception towards a particular behaviour that is influenced by the responses of significant others e.g. family, friends; Motivation to comply- taking others' responses into consideration and deciding whether one should or should not perform a particular behaviour) 3. Perceived behavioural control (Perceived behavioural control- an individual's perceived ease or difficulty of performing a particular behaviour [as determined by control beliefs]; Control beliefs- an individual's belief towards the presence of factors that facilitate or prevent the performance of a given behaviour) 4. Behavioural intention (An individual's readiness to perform a given behaviour based upon attitude, subjective norm and perceived behavioural control)

<p>Transtheoretic al Model (TTM)</p>	<p>TTM assesses an individual's readiness to alter their behaviour and adopt new healthier behaviours through a number of stages of change. There are five 'stages of change':</p> <ol style="list-style-type: none"> 1. Precontemplation- the individual is most likely to be unaware that their existing behaviour may be of concern and has no intention of modifying their behaviour (usually measured as the next six months) 2. Contemplation- the individual is considering making a change whereby they are likely to be aware of benefits of changing their behaviour; however they may also be aware of the costs as well. 3. Preparation- individual is intending to make a change in the immediate future and may have already taken steps to change behaviour. These individuals are now prepared for 'action' and placed on health promotion initiatives e.g. health education programmes. 4. Action- this is the stage where individuals engage in making behavioural changes that will endeavour to reduce the risk of disease or deterioration in their current health condition. Throughout this stage individuals are susceptible to relapse. 5. Maintenance- individuals prevent relapse and continue with behavioural changes they have implemented during 'action'. They eventually become less concerned with relapsing and become confident they can continue with their behavioural change. 	<p>There are a number of techniques that may be used throughout TTM to guide individuals from one stage to the next:</p> <ol style="list-style-type: none"> 1. Consciousness raising- increasing awareness e.g. provision of greater information, education 2. Dramatic relief- generating an emotional response e.g. a feeling of hope and inspiration when hearing stories of how other individuals (like themselves) have made similar behavioural changes 3. Environmental revaluation- the realisation that unhealthy behaviours may also have a negative impact on others 4. Social liberation- the realisation that society is more supportive of healthy behaviour 5. Self re-evaluation- the individuals realisation that behaviours (healthy or unhealthy) play an important part on who they are and how they may be perceived by others 6. Stimulus control- using reminders to encourage the adoption/ maintenance of healthy behaviours 7. Helping relationships- having someone to talk to that is supportive of the individual's behavioural change 8. Counter conditioning- replacing unhealthy behaviours and thoughts with healthier alternatives 9. Reinforcement management- greater incentives for healthy behaviours in comparison to unhealthy behaviours 10. Self liberation- individual's belief that they have the ability to change and making commitments to act on that belief
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Self Determination Theory (SDT)	SDT is a theory that highlights the role personality development and behavioural self-regulation can have upon an individual's intrinsic motivation, social development and well-being (Ryan and Deci, 2000).	<ol style="list-style-type: none"> 1. Intrinsic motivation- the natural inherent drive within individuals to alter their behaviour because they find it interesting or enjoyable 2. Extrinsic motivation- motivation that is external from the individual and can generate a separable outcome 3. Autonomy- an individual's desire to exercise choice and feel that they are in control of their own actions 4. Competence- an individual's ability to perform certain behaviours and accomplish desired outcomes 5. Relatedness- an individual's need to feel a sense of belonging and connectedness to others
Social Cognitive Theory (SCT)	SCT provides a framework of understanding, predicting and changing human behaviour. SCT considers human behaviour to be based upon personal factors, behaviour and the environment.	<ol style="list-style-type: none"> 1. Environment- factors that are external to the individual that may provide opportunities and social support for behavioural change 2. Situation- individual's perception of the environment 3. Behavioural capability- the acquisition of knowledge and skill to perform a given behaviour (provision of skills training) 4. Expectations- the acknowledgement of all possible outcomes for a given behaviour (particular attention paid to positive outcomes of adopting healthier behaviours) 5. Expectancies- the values placed on a given outcome 6. Self-control- individual self-monitoring of behavioural change (Opportunities for goal setting, problem solving, self-reward) 7. Observational learning- Changing behaviour by watching others perform an action/behaviour and observing the outcomes that result from a given behaviour (e.g. use of role models) 8. Reinforcements- responses to a person's actions that encourage the continuation of healthier behaviours and discourage unhealthy behaviours 9. Self-efficacy- an individual's perception that they can successfully perform a behaviour that will have positive outcomes (or outcomes they desire)

2.5.2 Bandura's interpretation of self-efficacy

A prominent concept that is present within self-management interventions is self-efficacy, either as a technique used to encourage behavioural change or as an outcome measure. The role of self-efficacy is complex and more than an individual's perception that they can successfully perform a behaviour that will have positive outcomes (Bandura, 1977). The concept is linked with an individual's perception that they are able to influence their motivation to make behavioural changes in a given social environment. The foundation of the principle is based on an individual's intentions and the ability to act on those intentions (Bandura, 1990). The ability to act on intentions is often separated into a number of different stages; a stage where people begin to consider changing their habits, the effort required to make a change, the barriers that prevent an individual making a change and how they intend to maintain behavioural changes (Bandura, 1990: 10).

Individuals with a strong sense of self-efficacy see problems that need to be mastered, develop a strong sense of commitment to tasks, and recover well from setbacks. In contrast, people with a weak sense of self-efficacy often feel that instigating and making behavioural changes are beyond their control and quickly lose confidence in their own abilities (Bandura, 1997). However, Bandura's interpretation and explanation of self-efficacy can de-emphasise the role social factors can play when implementing behaviour change (Biglan, 1987).

Furthermore, self-efficacy fails to consider the extent that failed attempts to make behavioural changes have upon an individual's emotional well-being and how future attempts to make behavioural changes are dependent on past successes throughout a person's life, such as academic performance, career choice and/or social performance (Maibach and Murphy, 1995).

2.5.3 Empowerment theories

Another common underlying theory used within behavioural change interventions is empowerment. Empowerment, with regards to health promotion, refers to individuals gaining control over decisions that affect their health. Empowerment theory aids people's ability to set goals and develop the necessary skills to achieve these goals. The empowerment approach is a bottom-up approach that allows the individual to identify their own concerns and gives them the skills and attributes to act upon them (Naidoo and Wills, 2000: 98).

There are two types of empowerment theory often used. Self-empowerment places the individual at the centre and aids the individual to increase control over their health.

Community empowerment can be developed through designing a programme of action based around a community's concern for health. Ferreira and Castiel (2009) argue that many varying groups co-exist within one community, therefore it is extremely difficult to tailor a programme of action that will result in benefits for all groups.

2.5.4 Behavioural change techniques

Chronic disease self-management interventions use a range of behavioural change theories but they also incorporate a range of techniques. Interventions, and subsequently those delivering interventions, use a range of behavioural change techniques to encourage participants to adopt healthier behaviours. Abraham and Michie (2008) have attempted to depict how certain behaviour change techniques encourage behavioural change, developing a 26 item checklist of techniques used in various health interventions (Appendix 1). Further taxonomies have been developed by Michie *et al.* (2010; 2011) that have a greater number of techniques, but they are based on interventions concerning smoking cessation, increasing fruit/vegetable

intake and physical activity. The results from Abraham and Michie (2008) systematic analysis demonstrated 23 out of 26 techniques were reliable in defining techniques used within interventions based on 195 articles that provided detailed descriptions.

There are some limitations with regards to the application of this checklist when determining which techniques lead to potential behavioural changes by patients. Firstly, the checklist is dependent upon the descriptions and details provided by authors regarding their respective interventions, where Davidson *et al.* (2003) has stated the specific information that should be reported by authors in published reports. Secondly, the 26 item checklist is based on self-management interventions that have been designed for adults targeting specific behaviours e.g. weight loss. Thirdly, many have stated that such an exhaustive list of definitions is too simple to apply to complex theoretically-founded interventions (West *et al.*, 2010). Finally, the application of such techniques is dependent on the knowledge and skill of the researcher. Behaviour change techniques and theories have been criticised for being constructed on a single unifying theory of motivation i.e. behavioural change techniques that influence how an individual behaves to achieve a specific behavioural goal (Webb *et al.*, 2006). Consequently, behaviour change taxonomies are not measuring the effectiveness of interventions that encourage behavioural change, but the individual's intention to make behavioural changes towards their health.

2.6 LIVING WITH CHRONIC CONDITIONS- THE SOUTH ASIAN EXPERIENCE

2.6.1 Differences within the South Asian population

There are four predominant South Asian communities living in the UK at present: Muslims from Pakistan (mainly from the state of Punjab, Sindh or Jammu and Kashmir), Sikhs from northern India (from the state of Punjab), Hindus from central India (from the state of Gujarat), and Muslims from Bangladesh (from the state of Sylhet). Muslims from Pakistan, Sikhs from India and Muslims from Bangladesh, in their majority, were part of the mass migration movement of the 1950s and 1960s, eventually residing within large inner cities and regions such as the West Midlands, Manchester, Bradford, Glasgow and London (Khunti *et al.*, 2009). Many members of these communities have experienced considerable social mobility, but the majority are still likely to reside in deprived inner-city areas and have low paid occupations.

2.6.2 Cultural lifestyles: Diet, exercise and practices

The dietary choices made by individuals from various South Asian groups are diverse. The most commonly cited difference is the use of cooking oil, ghee or butter for the preparation of Asian meals (McKeigue *et al.*, 1985). The use of ghee (or clarified butter), in the past, was in common use within most South Asian communities, particularly Bangladeshi and Punjabi communities. Recently, the use of cooking oil and/or butter is commonly used in Punjabi households, with ghee rarely used by South Asians residing in the UK (Kassam-Khamis *et al.*, 1995). Nevertheless, a South Asian diet does contain more carbohydrate, less fat and protein and more fibre than a western British diet. The attitudes members of this community have towards their staple South Asian diet are varied. A study by Lawton *et al.* (2008) of the eating

practices of British Pakistanis and Indians with type 2 diabetes found that individuals from both respective communities continued to consume South Asian foods although they knew that they were detrimental to the management of their chronic diseases.

A key finding of Lawton *et al.* (2008) was the level of input male participants had with regards to ingredients used in the preparation of meals, as it had previously been reported that men had little or no input into how meals were prepared. The diets of South Asian populations have changed given the presence of British-born descendants within households. This has led to the inclusion of more western meals and foods, where western foods are understood to be convenience or processed foods that involve little or no preparation (Nazroo, 2003). Punjabi individuals (from Pakistan or northern India) will often use wheat as their staple carbohydrate source in a chapatti based diet, whereas Bangladeshi individuals will have a staple diet of rice and fish. Conversely, across all three major South Asian sub-groups the consumption of meat is considered unhealthy or prohibited due to a perceived high fat content or forbidden because of religious doctrine.

One of the starkest differences within South Asian sub-groups relates to smoking patterns. Bangladeshi and Pakistani individuals are much more likely to smoke tobacco, as well as other tobacco products, than Indians (Nazroo, 1997). Although women are reported to smoke less frequently than men, women from the Bangladeshi and Pakistani communities are much more likely to have smoked in the past or be current smokers compared to their Indian counterparts. Individuals from the Bangladeshi population are more likely to consume chewing tobacco, in particular betel nut that is part of popular paan masala snacks. There is a

lower prevalence of reported smoking in the Sikh community in comparison to other South Asian groups and the native British population (McKeigue, 1988).

2.6.3 Health beliefs: The influence of religion and culture on beliefs and practices

Religion plays a considerable role in the beliefs and practices of South Asian individuals.

Muslims are expected to follow a 'halal' diet (only eating animals with a cloven hoof who are slaughtered in a particular way), Hindus have a greater preference for the use of ghee, which is considered a sign of wealth, while Sikhs are given guidelines in the holy text, the *Guru Granth Sahib Ji* and are very often vegetarian (Beishon and Nazroo, 1996; Johnson, 2004).

Muslims are forbidden to drink alcohol while Sikhs are forbidden to consume or inhale intoxicating substances i.e. drinking alcohol and/or smoking substances.

The most commonly cited health beliefs among the South Asian population are fatalistic beliefs i.e. the belief that a greater power has control over an individual's actions which the individual is unable to change or influence. A study conducted by Darr *et al.* (2008) on illness beliefs of South Asian and European patients living in the UK found that Hindus and Muslims in the study were much more likely to cite fatalistic beliefs as a reason for being diagnosed with a chronic disease, but less so with Sikhs. The issue this highlighted was the potential shift of the locus of control away from the patient which inevitably leads to reduced motivation and confidence to effectively self-manage chronic diseases. Stress is also a prominent belief cited by South Asians as the sole or biggest factor that contributes to the onset of chronic diseases. Stress is intricately affected by social factors such as low income, isolation from family members and job strain i.e. the level of control over the type of occupation and/or employment position an individual is able to fulfil (Hemingway *et al.*,

2001). A study with Sikh men suffering from heart disease recognised that living with a chronic illness in a western society can be a stressful experience, as older patients feel they have a diminished role within their household and have a greater dependency upon their children (Bedi, 2008).

Religious and cultural beliefs also influence the type of treatment South Asian individual's desire, as members of this group often prefer to access alternative therapies to treat illnesses. South Asian individuals often use alternative therapies as supplementary medication rather than an alternative to western medication. Accessing alternative therapies frequently comes from first generation migrants holding sceptical beliefs towards the effectiveness of western medicine (Ismail, 2005).

2.7 MANAGEMENT OF CHRONIC DISEASE: BEHAVIOURAL CHANGE INTERVENTIONS AND CHRONIC DISEASE SELF-MANAGEMENT PROGRAMMES

2.7.1 Chronic disease self-management programmes (CDSMPs): The Stanford Model

Chronic disease self-management programmes (CDSMPs) are interventions designed to encourage individuals to take control of the day-to-day care of their chronic illness through the implementation of health education messages (Lorig and Holman, 2003). The Stanford Model, developed by Kate Lorig and colleagues and which many other behavioural change interventions have been modelled upon, was based on interventions designed to aid better self-management for arthritis patients. The aim is to change patient attitudes towards their own ability to manage their condition and help them to develop the necessary skills to self-manage (Lorig *et al.*, 1994).

The Stanford model for CDSMPs is a group patient education course delivered by trained lay leaders (Sobel *et al.*, 2002). The intervention is delivered once a week for approximately six weeks, in primary care and community settings. The underlying theory of CDSMPs is to focus on the patient's self-defined needs in relation to common symptoms that are experienced with the majority of chronic conditions such as pain, fatigue and emotional distress. In order to help patients develop the necessary skills to self-manage, the Stanford model was based on social cognitive theory and specifically Bandura's (1977) understanding of the concept of self-efficacy. The first lay-led CDSMPs were condition specific interventions, for example interventions designed for arthritis patients with outcomes measuring pain and physical functioning (Barlow *et al.*, 2002).

Much of the criticisms of Lorig *et al.* (1999) work relates to the effectiveness of CDSMPs in various contexts, settings and populations. The most prominent criticism is based on the finding that patients who attend the CDSMP use less health care services post intervention (Lorig *et al.*, 1999) which subsequently reduces the overall cost of health care. This finding has not been reproduced in subsequent trials of CDSMPs, where in contrast some studies have found that patients increase engagement with health professionals after attending a health intervention (Greenhalgh *et al.*, 2005). Many of the trials conducted by Lorig *et al.* were in predominantly White populations with health insurance, and therefore the effectiveness of CDSMPs in improving self-management skills with patients from socio-economically deprived areas is uncertain (Osborne *et al.*, 2008).

2.7.2 What CDSMPs have been delivered in the UK?

A range of CDSMPs have been delivered in UK health settings in the recent past. This chapter provides a short overview of five chronic disease self-management interventions that have been delivered throughout the UK in various locations and have produced varying results. A systematic review (Chapter 3) will provide greater analysis with regards to lay-led CDSMPs designed for minority-ethnic populations. Tables 2 and 3 provide a description of published evaluations of the CDSMPs delivered in the UK.

Table 2. Description of self-management programmes delivered in the UK

Author(s)	Components of intervention	Cultural Adaption of Intervention	Frequency/length of intervention	Description/Training of lay person	Intervention Behavioural Change Theory
Kennedy et al (2007)	Sessions were based on relaxation, diet, exercise, fatigue, breaking the 'symptom cycle', managing pain and medication, and communication. Session included goal setting and action planning, including an assessment of self-efficacy.	Delivered in English (anglicised version of Lorig CDSMP)	6 weekly sessions lasting 2.5 hours each Intervention delivered in non-NHS settings	Intervention taught by a pair of lay trainers or volunteer tutors who were trained and subject to quality assurance. Interventions were delivered according to a written manual.	Social learning theory (similar to social cognitive learning and based on the concept of self-efficacy)
Deakin et al (2006)	Sessions aimed to develop skills and build confidence, to make informed decisions regarding diabetes self-care	Delivered in English and Urdu Separate sessions were held for Urdu speaking Asian participants, with a translator present	6 weekly sessions lasting 2 hours each Sessions delivered in community centres. Average of 16 participants with four to eight carers.	The X-PERT programme was designed and delivered by diabetes research dietician who took on the role of a diabetes educator.	Empowerment theory
Davies et al (2008)	Sessions were elicited rather than taught, ensuring a non-didactic approach. Curriculum focused on lifestyle choices, food choices, physical activity, cardiovascular risk factors, medication as self-management strategy	Delivered in English.	Programme was 6 hours in duration delivered in either one day or two half day segments.	Delivered by registered healthcare professionals who received formal training. There was an internal and external assessment to ensure consistency. Programme is facilitated by two educators.	Leventhal's common sense theory, the dual process theory, social learning theory. Philosophy of the programme founded on patient empowerment.

Barlow et al (2000)	<p>The curriculum is based on; information about arthritis, an overview of self-management principles, exercise, cognitive symptom management (e.g. distraction, visualisation, and guided imagery), dealing with depression, nutrition, communication with family and health professionals, and contracting.</p> <p>The intervention involves goal setting. Format is largely interactive, with 'short lecturettes' to introduce topics, group discussion, problem solving, role plays and mastery experience.</p>	Delivered in English	6 sessions lasting 2 hours each. Delivered in community settings.	Delivered by lay leaders (with the majority suffering from arthritis) with the aid of The Arthritis Helpbook. Training provided by Arthritis Care.	Bandura's Self Efficacy theory.
Buszewicz (2006)	The intervention group received a booklet designed for the study and included information from Arthritis Care and the Arthritis Research Campaign.	Delivered in English.	6 sessions lasting 2 hours each. Delivered in primary care settings.	Delivered by lay leaders.	Bandura's Self Efficacy theory.

Table 3. Summary of findings for published interventions

Study	Study Design	Participants	Outcome Measures	Main Findings
Kennedy et al (2007), Expert Patients Programme National, UK	RCT (Randomisation 1:1) N=629 White English participants with one of more chronic conditions F/U 6 months	General population (majority White population) Multiple conditions (33.9% suffering with musculoskeletal condition) Intervention (mean age 55.5 years, 70% female, 24.6% without any qualifications) Control (mean age 55.3 years, 69.6% female, 19.3% without any qualifications)	Primary outcomes (self-efficacy, energy, health care visits) Secondary outcomes (general health, social role limitations, pain, psychological well-being, health distress, exercise, partnership with clinicians, diet, complementary products, relaxation, information seeking)	Intervention group reported sizable improvements in self-efficacy and energy but no differences in health care utilisation compared to the control group. With regards to secondary outcomes intervention patients demonstrated significant improvements in social role limitations, well-being, lower health distress, increased levels of exercise and relaxation and greater partnership with clinicians. There were no differences between groups on general health, pain, diet, use of complementary products or information seeking.
Deakin et al (2006), X-PERT North England (Lancashire, UK)	RCT (Randomisation) N=314 F/U 4 and 14 months	General population (majority White and Asian Pakistani population) Type 2 diabetes Mean age 61.5 years, 48% women, mean duration with T2DM 5 years, 83% had left school at age 16 or less)	Primary outcome (glycated haemoglobin), BMI, diabetes knowledge (14 items), nutritional intake, diabetes self-care activities, frequency of physical activity, blood glucose testing and foot care. Diabetes treatment satisfaction, quality of life, diabetes empowerment scores.	82% (N=128) completed four or more sessions. At 14 months the intervention group compared to the control group showed significant improvements in mean HbA1c. The number needed to treat for preventing diabetes medication increase was 4. Intervention patients showed significant improvements for body weight, BMI, waist circumference, total cholesterol, self empowerment, diabetes knowledge, physical activity levels, foot care, fruit and vegetable intake and treatment satisfaction.

Davies et al (2008), DESMOND	Multicentre cluster randomised controlled trial	General population (majority White population)	Main outcome measures (Haemoglobin A(1c) levels, blood pressure, weight, blood lipid levels, smoking status, physical activity, quality of life, beliefs about illness, depression, emotional impact of diabetes)	Haemoglobin A(1c) levels at 12 months had decreased by 1.49% in the intervention group compared with 1.21% in the control group. After adjusting for baseline and cluster, the difference was not significant. The intervention group showed a greater weight loss: -2.98 kg (95% confidence interval -3.54 to -2.41) compared with 1.86 kg (-2.44 to -1.28), P=0.027 at 12 months.
England, UK	N=824 F/U 12 months	Type 2 diabetes Mean age 59.5 years, 45% women		The intervention group showed significantly greater changes in illness belief scores (P=0.001); directions of change were positive indicating greater understanding of diabetes. The intervention group had a lower depression score at 12 months: mean difference was -0.50 (95% confidence interval -0.96 to -0.04); P=0.032. A positive association was found between perceived personal responsibility and weight loss at 12 months (P=0.008).
Barlow et al (2000) Throughout UK	RCT (randomisation into intervention and waiting list control) N=544 (Intervention N=311, Control N=233) F/U 4 and 12 months	General population (majority White population, intervention 98% Caucasian, control 94% Caucasian) Arthritis Intervention (mean age 57 years, 85% female) Control (mean age 57 years, 83% female)	Primary outcomes not stated. Other outcomes (arthritis self-efficacy, cognitive behavioural techniques, physical health status, anxiety and depression, psychological well-being, use of health care resources, visits to GP)	At 4 months intervention group showed significant improvement on arthritis self-efficacy for other symptoms and pain subscales. Intervention group also showed greater significant improvements in health behaviours (cognitive symptom management, communication with physicians, dietary habit, exercise and relaxation). In addition participants were significantly less depressed and had a greater positive mood. Similar findings were found in the intervention group at 12 months follow-up, although there was a significant improvement on pain and visits to GP had decreased.

Buszewicz (2006)	RCT (Randomisation into intervention or control arm.	General population (majority White population, intervention 100% White, control 99% White)	Primary outcome (quality of life, SF-36)	Response rates were 80% and 76% at four and 12 months. The two groups showed significant differences at 12 months on the anxiety sub-score of the hospital anxiety and depression scale (mean difference -0.62, 95% confidence interval -1.08 to -0.16), arthritis self-efficacy scale for pain (0.98, 0.07 to 1.89), and self-efficacy for other aspects of management (1.58, 0.25 to 2.90). Results were similar for intention to treat and per protocol analyses. No significant difference was seen in number of visits to the general practitioner at 12 months
England, UK	N=812	Arthritis (adults over the age of 50 clinically diagnosed with osteoarthritis of the knees or hips or both)	Other outcomes (pain, stiffness and functional disability, self-efficacy, anxiety and depression)	
	F/U 4 and 12 months	Intervention (mean age 68 years, 63% female) Control (mean age 69 years, 63% female)		

The Expert Patients Programme (EPP) is the most well-known and extensively delivered chronic disease self-management intervention delivered in the UK, and it is described as an anglicised version of the original CDSMP developed by Lorig *et al.* at Stanford University. The aim of the programme is to deliver self-management support and improve the quality of life of people with long-term conditions by developing skills and patient confidence (Rogers *et al.*, 2008: 21). The EPP intervention was commissioned by the NHS but often delivered by community interest companies, delivered in primary care and non-NHS settings. The evaluation of EPP highlighted a number of limitations. The results, based on self-reported data from patients and a sub-group analysis, failed to detect any effect in results by health conditions (although the trial was not powered to detect interactions). Furthermore, the results demonstrated no effect on health care utilisation over 6 months as reported by Lorig *et al.* (1999).

An analysis of the EPP by Wilson (2001) critiqued the notion of ‘expert patients’ and the apparent paradox of individuals being simultaneously self-reliant and compliant. Wilson (2001) questions the ability of interventions like EPP to transfer expertise, as individual behaviour is deeply embedded within a social and historical context, stating individual behaviour is determined by conflicting expectations from health professionals and society. A study conducted by Wilson *et al.* (2006) with patients attending self-management courses, with the majority attending EPP, found that patient attitudes strongly related to medical professionals perceptions towards an ideal patient. Yet, the EPP had a ‘Foucauldian potentiality’ by medicalising self-care practices and bringing them into a person’s home (Wilson *et al.*, 2007: 437). Therefore, it was felt that patients were developing skills health

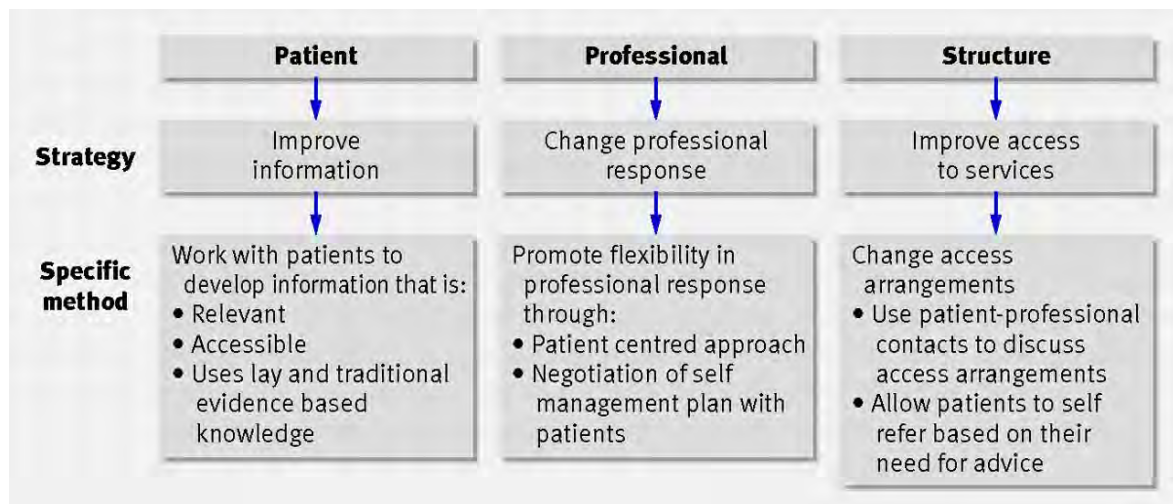
professionals wanted them to practice rather than gaining skills identified by their own personal needs.

Griffiths *et al.* (2007) argues that there may be several reasons why lay-led programmes delivered in the UK fail to reduce health care utilisation. Firstly, CDSMPs encourage clearer and effective communication with medical practitioners, and this may lead patients to consult more. In the UK there is free health care provision unlike other countries where CDSMPs have been evaluated i.e. US, China, Netherlands. Griffiths *et al.* (2007) have questioned the importance of self-efficacy as an outcome measure and how long the effects of self-efficacy last. Finally, CDSMPs have continued to show significant improvements in non-clinical outcomes rather than clinical outcomes; thus, lay-led CDSMPs may benefit from medical professionals delivering content focussing on better clinical disease management skills.

2.7.3 The WISE approach (the whole system informing self-management engagement model)

The WISE approach was developed to discover why recent interventions designed for patients suffering from chronic diseases only showed limited improvements in clinical and non-clinical outcomes (Kennedy *et al.*, 2007). The WISE approach follows a chronic care model that rejects the notion that self-care can be limited to attending self-management classes (Wagner, 1998) but should be based on greater engagement between patients and service providers and how both groups understand and treat chronic conditions. Kennedy *et al.* (2007) developed a model that encouraged health professionals to be more responsive to patient needs, detailing the role of the patient, practitioner and structure. An example of an intervention based on a whole systems perspective is presented in Figure 3.

Figure 3: Example of an intervention based on whole systems perspective



Kennedy A *et al.* BMJ 2007; 335:968-970

The model places greater attention on a patient's social situation. This contrasts with interventions which are primarily based on psychological behavioural change theories and place greater importance on individual beliefs. The WISE approach states that interventions need to have greater consideration of the context in which patients self-manage, where interventions should allow individuals to discuss their background, socio-economic circumstances and family arrangements (Kennedy *et al.*, 2007). Greenhalgh (2008) builds on this idea of a whole systems approach, stating that interventions need to go beyond the clinic and into the community, via the provision of greater personalised self-management plans and support from practitioners. However, stakeholders may also have personal agendas that they wish to promote (Greenhalgh, 2008).

2.8 CULTURAL ADAPTATION WITHIN INTERVENTIONS

A systematic review of the effectiveness of lay-led group-based chronic disease self-management interventions for minority-ethnic populations in high income countries has been

conducted in the following chapter, which will discuss the relevance of cultural adaptations and their effectiveness. A number of behavioural change interventions have been designed specifically for minority-ethnic populations residing in deprived locations in the UK, most notably for South Asian populations.

2.8.1 Examples of culturally adapted interventions

A recent study by Greenhalgh *et al.* (2005) reports on a ‘story telling’ intervention designed for minority-ethnic individuals who were unable to speak English. A number of cultural adaptations were made to the intervention to encourage greater uptake and improve suitability. The intervention was delivered in Tower Hamlets, London, an area with a large Bangladeshi community. The intervention employed ‘bi-lingual health advocates’ i.e. training local Bangladeshi individuals (including link workers and voluntary sector interpreters) to teach diabetes patient education. Previous research by the author had identified that members of this community preferred to learn by narrating their own experiences of illness and listening to others (Greenhalgh *et al.*, 1998). This programme was more than the provision of knowledge as the story telling approach allowed participants to repeatedly discuss and challenge information.

The *Khush Dil* (Happy Heart) intervention was designed to develop a culturally appropriate framework to help people from South Asian communities to manage CHD risk factors. The intervention was culturally adapted to include practical activities to encourage lifestyle change, with the inclusion of cookery classes, exercise classes and CHD/diabetes awareness sessions (Bhopal *et al.*, 2007).

These interventions highlight two important areas where cultural adaptations are made; delivery and the content provided within interventions. The recruitment of individuals from the same communities as patients is based on accommodating patient communication needs, perceived greater knowledge of beliefs and practices, and patients potentially feeling more comfortable and less anxious. In addition, workshops run by South Asian health workers encouraged greater attendance from participants in the aforementioned interventions. The inclusion of interactive workshops allows participants from South Asian communities to visualise 'healthy behaviours'. However, a more detailed critique is needed with regards to the employment of lay people to deliver self-management interventions.

2.8.2 What are the advantages and disadvantages of delivering interventions with lay people?

The definition of lay people within the context on this thesis is defined as people who have no recognised medical qualification and received no formal medical or health care training, but may have other health related qualifications. For example dietitians, nutritionists and podiatrists would not be considered as lay people, but peer educators would as they would receive some training and qualifications to deliver interventions. The emergence of lay workers effectively delivering CDSMPs originated from Kate Lorig's early work that compared the effectiveness of delivering interventions with lay leaders and professionals, where results showed that both lay and professional led groups resulted in improvements in outcome measures (Lorig *et al.*, 1986).

There are some notable differences between lay people and professionals delivering CDSMPs to patients suffering from chronic illnesses. Within a UK context, the development of lay

workers (also referred to as non-professional health workers) is embedded in the Department of Health's (2001) development EPP. The role of the non-professional health worker differs from a professional role, as it does not require extensive medical knowledge through numerous years of professional education and experience, but specific chronic disease self-management training. These courses train the lay person to make an accurate assessment of the patient's self-management capacity, outline the key issues and problems the patient has with their chronic condition and provide client-based goal setting. This incorporates the need for integrated care planning, outcome measurement and motivational techniques that enable the lay person to influence a patient's internal motivation to change (Kubina, 2007).

A vital component of lay people being recruited to deliver self-management interventions was their own experience of living with chronic conditions. It was perceived that this would lead to lay workers developing mutually beneficial relationships with the patient, as the patient can relate to the health worker and be able to express their attitudes more openly, as initial perceived 'us and them' barriers are surpassed (Macdonald *et al.*, 2009).

Individuals that are attracted to lay positions differ from those who are attracted to other roles in health care. A study of lay educator's preferences for delivering EPP found that individuals wished to pursue personal goals, increase their knowledge on chronic illnesses and self-management and improve their career prospects. Therefore, people who are attracted to and occupy lay roles in CDSMPs wish to gain valuable experience and develop skills and knowledge that could give them the opportunity to apply for other roles within the health care sector (Macdonald *et al.*, 2009). Conversely, there were a number of participants in Macdonald *et al.*'s study who expressed altruistic attitudes and working with patients to build

their self-esteem as reasons for delivering EPP. Lake and Staiger (2009) state that people who suffer from chronic diseases when recruited to a lay educator role rely more on their personal experiences rather than training they have been given.

According to Mitchell (2009), the approach adopted by lay workers to deliver health interventions differs to the approach taken by professional workers. Lay workers are considered to be more informal, intentionally delivering courses with less structure and professional workers are more didactic in their approach. Lay workers are able to spend a greater amount of time with patients; allowing people to discuss their emotional concerns as well as gaining valuable knowledge to self-manage. This approach is said to be welcomed by patients, as a recent study on patient attitudes towards the management of type 2 diabetes cited a lack of time with health professionals as an aspect of care that was left unfulfilled (Pooley *et al.*, 2001). The notion of trust has also been identified as a core element of the relationship between the health worker and patient (Kearley *et al.*, 2001). Greenhalgh *et al.* (2005) proposes that trust is often built through repeated encounters over a period of months; as CDSMPs are delivered over a number of weeks it is imperative lay workers are able to build 'trustworthy' relationships within a short space of time.

2.8.3 Group-based versus one-to-one interventions

A central element of chronic disease self-management interventions is the group-based format. The perceived benefit of having a group-based format is the ability a) for a single lay worker to see a greater number of individuals, making the service much more cost effective compared to one-to-one self-management interventions and b) it enables patients to interact with each other, sharing personal narratives and tips and techniques to manage their disease

(Lorig *et al.*, 1996). In definition a group can be the presence of more than a single individual; however, with regards to health education, a group should consist of 2-20 members with an average of 10 people (Rickheim *et al.*, 2002).

A health technology assessment by Loveman *et al.* (2008) evaluated the clinical and cost effectiveness of patient education models for diabetes. This review included 24 studies (18 randomised controlled trials and 6 controlled clinical trials). Patients who received group care showed improvement in diabetes quality of life measures and HbA1c levels, but these results were not considered to be of a magnitude that is clinically significant. A qualitative review conducted by Norris *et al.* (2001) on individual versus group-based care for diabetes self-management education found that both approaches led to improvements in self-care behaviours, with group care patients showing greater improvements in nutritional management and physical activity. Norris *et al.* (2001) concluded that both approaches provide unique and distinct benefits.

2.9 POLICY LITERATURE

2.9.1 The role and aim of health promotion

Chronic disease self-management programmes are based within the field of health promotion, an area which encourages individuals to take action over factors that influence their health and will lead to an improvement in their quality of life (Ottawa Charter, 1986). Depending on the model of health promotion chosen, CDSMPs may also be based on non-individual approaches such as the empowerment theory or community level action (Public Health Agency, 2009). The first clear objective for improving the health of individuals across the world was outlined by the Ottawa charter in 1986, which defined health as a positive concept

that goes beyond the individual's physical condition but also includes improving their emotional well-being. The charter established a list of eight fundamental conditions and resources required for good health (Ottawa Charter, 1986): peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity.

Recently, it has been increasingly difficult to define what exactly healthy public policy is (Bunton, 2002). Buse *et al.* (2005) interpret health policy as the courses of action that affect the set of institutions which constitute all sections of the health system. Whereas Walt (1994; 2008) defines health policy in terms of process and power; which is centrally concerned with who influences the policy making process. While policy is perceived by many to be a top-down process, individuals and groups are important vehicles as they can set the terms of political debate and shape the policy agenda; hence, the voting public is not merely subject to policy outcomes but bear a considerable influence in its construction (Baggott, 2007).

2.9.2 The national approach to self-management

In the recent past, the UK government has paid considerable attention to support people living with long-term conditions. The white paper *Saving Lives: Our Healthier Nation* reported that individuals suffering from long-term conditions need to develop skills and recognise the signs when their symptoms are getting worse (Department of Health, 1999).

UK policy towards lay-led self-management intervention was based on the former chief medical officer, Sir Liam Donaldson, learning from Lorig and colleagues (1996) work on CDSMPs and subsequently developing the Expert Patient Programme as an 'innovative solution' to tackle long-term conditions (Donaldson, 2003). As a result, a rapid review of the

current state of knowledge regarding lay-led self-management of chronic illness was undertaken by Bury *et al.* (2005) for the National Institute for Health and Clinical Excellence (NICE). The aim of the review was to provide a guide to current evidence rather than an evaluation. There were a number of findings from the review. Firstly, sociological studies have identified that the management of chronic disease is dependent on a wide range of factors e.g. the availability of family support, while determinants such as age, gender and ethnicity play an important role towards an individual's interpretation and approach to self-management. The review also stated that lay-led self-management interventions have led to improvements in certain outcomes for White European groups, but remains inconclusive for non-European groups, citing a need for further research.

The review also highlighted a number of issues with regards to the delivery of CDSMPs. There is no systematic referral process for patients to attend CDSMPs, as interventions often resulted in patients self-referring. Lay-led interventions are more likely to attract patients from particular backgrounds, i.e. well educated, English speaking women. Indeed, Lorig *et al.* (1999) found that non-English speaking people were less likely to attend CDSMPs.

The development of lay-led self-management interventions, in a UK context, has ultimately been influenced by the recent political climate and the need to reduce the cost of treating people living with chronic diseases. Consequently, the promotion of CDSMPs is partly based on the perception that it is cost effective to see more patients in a group rather than individually. Nevertheless, it remains difficult to justify this statement given the limited number of CDSMPs that have been conducted with economic evaluations in a UK context.

Another report, conducted by the Health Foundation, reviewed the evidence on whether it is worthwhile to support self-management as an effective method to manage long-term conditions (de Silva, 2011). The report found that self-management interventions not only help the individual to change their own behaviour, but that of their immediate family also. ‘Proactive education’ led patients to be more involved in the decision making process, along with addressing the emotional impact of living with their illness. de Silva (2011) did have concerns with regards to delivery of health information and how much patients wanted to become collaborative partners in the decision-making process.

2.9.3 Research with ‘at risk’ populations

The definition of an ‘at risk’ population is people who are more likely to develop a disease or illness due to physiological, hereditary or environmental factors (Zimmet *et al.*, 2005). People from minority-ethnic groups are often underrepresented in health research, particularly cardiovascular research (Gill *et al.*, in press). A problem with understanding the needs of at risk populations is their lack of engagement with research. A recent paper on the uptake of South Asian people in clinical trials found that participation was influenced by mistrust and cultural-religious reasons, while those participants who were fluent in English were ‘cherry-picked’ to take part (Hussain-Gambles *et al.*, 2003). Health professionals included in the research expressed a lack of time and resources to encourage participation from the South Asian population.

Further studies have reported similar findings, where communication and cultural difficulties are commonly reported (Rhodes and Nocon, 2003). One study, conducted by Jolly *et al.* (2005) on the attendance of ethnic minority patients in cardiac rehabilitation, found that

language and health issues contributed to non-attendance. Apart from research with South Asian groups, little evidence is available on participants who reject the opportunity to attend or drop out of clinical trials or interventions (Gatrad, 1997); participants who could benefit the most from attending self-management interventions. As a result, I intend to include members of the Sikh community in my research; a community that has had little involvement in studies investigating perceptions of chronic disease and self-management (Gatrad *et al.*, 1997; Worth *et al.*, 2009).

2.10 THEORETICAL LITERATURE

2.10.1 Introduction

Sociological theories have been used in the past to gain a better understanding of the experience of living with a chronic illness (Bury, 1982; Corbin and Strauss, 1985; Strauss, 1975; Williams, 2000). These studies highlight that living with and managing a chronic disease is experienced within a biographical context. As the vast majority of participants included within studies included in this thesis suffer from a long-term chronic illness, it is appropriate that a sociologically defined theoretical perspective be used to inform the interpretation of findings. Such an approach allows the researcher to interpret and compare findings from their research to existing knowledge and see whether findings agree or disagree with the existing literature (Herek, 1995).

As this study is constructed in two distinct phases, the evaluation of a health intervention and the inductive exploration of health beliefs in the Sikh population, the work of two key theorists could be useful. The body of work developed by Paulo Freire can inform the interpretation of findings by attempting to understand the socio-cultural impact of

disadvantaged, poorly educated communities attending a health intervention. The work of Michel Foucault and contemporary medical sociologists will be used to inform my interpretation of findings from patients attending the CDE programme and members from the Sikh population.

2.10.2 The work of Paulo Freire

Paulo Freire was a critical theorist, with much of his work influenced by the key principles of Marxism; the study of society through a social political perspective that is founded on a materialist interpretation of history and exploitation. His early work titled *Pedagogy of the Oppressed* (1970) was based on educational courses offered to poor, illiterate adult learners throughout Brazil during the 1950s and 1960s. Freire (1970) identified a number of key concepts within this literature such as praxis, dialogue, banking and conscientization. Praxis relates to individuals not only acknowledging their own social reality through gaining knowledge, but engaging in dialogue to critically reflect upon their social reality and take further action to improve it (Freire, 1970: 36-37). Freire's (1970) understanding of praxis was based on freedom and realisation by deprived illiterate communities from their existing struggles, something that Freire felt was a human condition.

Dialogue represents the equality, respect and trust individuals have for their fellow humans, where new knowledge and change can only occur through dialogue with others (Freire, 1970). Dialogue differs from conversation as it involves an evaluation of an individual's social reality and taking action to change it, through a language with those that understand their way of life, which is not only linguistically the same but based on a shared culture, history and identity (Freire, 1994). The banking concept refers to the process of passing knowledge from

those who are knowledgeable to those who know little or nothing, where the individual is understood to be a manageable, passive being that accepts the social reality that restricts him or her (Freire, 1970: 58-60). *Conscientization* (Freire, 1972) states cultural formation, knowledge creation and linguistic practices are central to enabling social change once humans have recognised the source of their oppression. For individuals who live in poverty or are illiterate, taking control over their future is difficult. As Freire (1972) argues, people may have accepted the 'values of the oppressors' and are unable to think critically to improve their social situation (Freire, 1972: 28).

There are some limitations to the concepts developed by Freire and his interpretation of education initiatives designed for deprived illiterate communities. Firstly, Freire fails to consider the positive nature of traditional educational practices and methods of teaching, where the aim is not to enable participants to realise and change their social reality but to improve their cognitive learning (Aronowitz, 1993). His binary interpretation of the oppressed and the oppressor (individuals who give and accept knowledge) is said to be too simplistic, where there are a number of divisions within these groups (McLaren and Leonard, 1994). Divisions may exist along class, gender and racial lines where members can simultaneously hold positions of being dominant and being oppressed (Glass, 2001).

However, even though Freire's work has been criticised, there is general agreement that education has the capability to enable individuals, either by themselves or as a collective group, to change their social reality. Paulo Freire and his work have been influential on adult educational research. For example, Wallerstein and Bernstein (1988) used a Freirean-based approach to compare traditional health education with a substance abuse prevention

programme in New Mexico, United States. Using the work of Paulo Freire, and the concepts outlined, I endeavoured to critically analyse components of the CDE programme, such as the style and delivery of educational content, the relationship between patients and educators and how patients interpreted the group experience of attending a lay-led self-management intervention given their social reality.

2.10.3 The work of Michael Foucault

Michel Foucault was a social theorist who established an extensive body of literature on power and knowledge, as well as other areas of social thought. In 1975, with the publication of *Discipline and Punish: The Birth of the Prison*, his work began to specifically focus on the concept of power. Power was understood as a notion of ‘discipline’ and uses the penal system as the context for his analysis.

The area which is most relevant to this study is the relationship between power, knowledge and the body. For Foucault, power was practiced by society and its subsequent institutions by encouraging individual self-surveillance, where the goal of such a practice is individuals acting as ‘docile bodies’; individuals who are disciplined and controlled (Foucault, 1975). The individual is subject to power relations that influence, either explicitly or subjectively, their ability to make informed decisions. To demonstrate his interpretation of discipline, Foucault (1975) uses Bentham’s *Panopticon*, an architectural design used in 19th century prisons to observe prisoners. The central feature of the panopticon was prisoners could never be sure if they were being observed at any given moment; therefore, individuals were more likely to be self-disciplined. In Foucault’s conceptualisation, power is not possessed by specific individuals that may occupy dominant positions, but rather manifested in the interactions

individuals have with each other and social institutions; power is not an absolute action but a relation, an action that influences another action (Foucault, 1975: 26-27).

Building on this, Foucault maintained that power was not only a tool of repression but it can have productive aspects, stating that not all power relations result in conflict (Weberman, 1995). Power relations are not one-sided affairs where the dominant group takes precedence over submissive individuals and exercised through a network of relations, but power plays a significant role in the construction of self.

Rose (1999) applies Foucault's interpretation of power to the area of public health, coining the term '*Healthism*'; the shift of responsibility from the state to the individual with regards to their health and well-being. For Rose (1996) individuals align their own beliefs and personal objectives with that of the state. Rose (1999) uses the example of individuals going to the gym perceived to be based on personal goals (e.g. improved fitness, physical appearance) but can also be understood as individuals being responsible; remaining free from illness and being able to work. As a result, the work of Foucault will aid the interpretation of participant's accounts of being healthy and understanding notions of responsibility.

2.10.4 The work of contemporary medical sociologists

Foucault wrote extensively on power and knowledge and other social theorists have also provided their own critiques. Lupton (1997), in *Foucault and the medicalisation critique*, proposes that individuals should not have their autonomy constrained by medical experts who exercise power over patients. Given the shift towards individualism in modern society, individuals' decision making abilities (with regards to health) are becoming more akin to

consumers rather than patients; shopping around for services that best fit their health needs (Lupton, 1995). Her paper *Consumerism, reflexivity and the medical encounter* (Lupton, 1997) with lay people across Sydney, Australia concluded patients' interactions with health professionals ranged from consumerist to passive behaviours dependent on personal desires and emotions. Although a consumerist position included patients who were critical, respondents still reported times when they would place their trust and faith in a particular doctor. The patient, as a consumer, is based on the assumption that individuals act like rational actors in the context of medical encounters. Lupton (1997) concludes that consumerism failed to comprehend the changing nature of the doctor-patient relationship, placing particular importance on doctors being able to fulfil emotional needs. Therefore, a patient's consumerist expectations are not only met by tangible needs e.g. getting a prescription, but having a 'consumption experience' based on how the doctor interacts with the patient (Lupton, 1997: 379).

Denise Gastaldo is a medical sociologist who has developed Foucault's work; specifically on the concept of bio-power and how it applies to health education. Gastaldo's interpretation of health education also builds on Freire's understanding, as she uses Brazilian state health education initiatives as context for her work. According to Gastaldo (1997) bio-power refers to mechanisms employed to manage the population and discipline individuals within a wider political context. Armstrong (1995) states that the implementation of health education created a new paradigm of surveillance medicine where it remains imperative that individuals recognise their 'at risk' state (Armstrong, 1995: 400). This inevitably places an expectation upon the individual to understand and make changes to become and remain 'healthy'.

There needs to be some consideration with regards to who creates this expectation of being healthy. According to Gastaldo (1997), government health policy defines what 'healthy' is, where practising healthy behaviours, is considered to be the norm. The concept of bio-power, and subsequently surveillance of health behaviours, is based on the power relationship between health professionals and patients. The recent political movement of promoting behavioural change highlights the connection between health education and bio-politics where health education is reinforcing public health policy guidelines (Gastaldo, 1997: 119). The content provided on health education courses is considered to be suitable to address patient needs, yet, content is not decided in consultation with patients but dictated to them. In addition, health professionals continue to play the dominant role within health education: controlling the content, discussions and outcomes patients wish to achieve from attending. Therefore, the work of Gastaldo and Lupton has shown how it is possible to apply and extend Foucault and Freire's concepts to the evaluation of contemporary public health services designed for socio-economically disadvantaged populations residing in the UK.

2.11 SUMMARY

This review of the literature demonstrates that there is a considerable detailed body of work on lay-led support for people suffering from long-term chronic diseases. Despite this level of extensive literature there remains very little research conducted with minority-ethnic populations residing in disadvantaged areas with regards to attitudes towards self-management and their experiences of attending self-management interventions.

Furthermore, given the limited research conducted with the Sikh population, a population who are prone to suffering from chronic diseases and showing limited participation in research, the

research presented in this thesis endeavours to address gaps in the literature. The next chapter describes findings from a systematic review evaluating the effectiveness of culturally adapted chronic disease self-management programmes for minority-ethnic populations. I narratively present findings, along with a critique of the value of cultural adaptations used in self-management interventions and reporting practices.

CHAPTER 3

3.0 A SYSTEMATIC REVIEW OF LAY-LED, GROUP-BASED SELF-MANAGEMENT INTERVENTIONS FOR MINORITY-ETHNIC POPULATIONS DIAGNOSED WITH DIABETES MELLITUS AND CARDIOVASCULAR DISEASE IN HIGH INCOME COUNTRIES

3.1 BACKGROUND

Migrant populations are more likely to suffer from long term chronic conditions than the general population. South Asians (originating from India, Pakistan and Bangladesh) are the largest minority-ethnic population in the United Kingdom (UK) (ONS, Census, 2001) and numerous in minority populations worldwide. The prevalence of chronic diseases, in particular type 2 diabetes (T2DM) and cardiovascular disease (CVD), is significantly higher in South Asian populations; in the UK, people of South Asian origin are six times more likely to develop T2DM compared to the general population and at an increased risk for CVD (Barnett *et al.*, 2006; Gill *et al.*, 2007).

Other ethnic groups prone to developing CVD, coronary heart disease (CHD) and diabetes mellitus (DM) include Latino, Hispanic, Mexican and African American populations residing in North America. Data from the United States (US) official records in 2007 stated the prevalence of diabetes was highest among African and Latino American populations (National Center for Health Statistics, United States, 2007). These groups have poor self-management behaviours, more likely to suffer complications with regards to their illness, and demonstrate higher utilisation of emergency healthcare services in comparison to other ethnic/racial groups (Bazargan *et al.*, 2003).

Over the past decade, in the UK, health policy has paid particular attention to promoting initiatives designed to help individuals with long-term conditions (Department of Health, 1999). This has led to the creation of various self-management programmes, such as the Expert Patients Programme (Kennedy *et al.*, 2007), X-PERT programme (Deakin *et al.*, 2006), DESMOND (Davies *et al.*, 2008) and many others. Chronic disease self-management programmes (CDSMPs) are interventions designed to encourage individuals to take control of the day-to-day care of their chronic illness through the implementation of health education messages (Lorig and Holman, 2003). Many chronic disease self-management interventions have been based on the Stanford Model, which consists of weekly group workshops, for approximately six weeks, in primary care and community settings. The intervention is delivered by trained non-health professionals or ‘peers’ who sometimes also suffer from a chronic illness. This model has been significantly adapted for different populations and resource circumstances. The interventions are designed to improve participants’ understanding and confidence, to enable them to adopt appropriate self-management behaviours, and have greater control over their diseases, which it is hoped will ultimately lead to a reduction in the use of healthcare services (Lorig *et al.*, 1999).

Lay-led interventions have been widely delivered in primary care and community settings to improve self-management behaviours amongst individuals suffering from chronic diseases (Newbould *et al.*, 2006; Norris *et al.*, 2002), evidence of the effectiveness of interventions using a group-based approach is inconclusive (Foster *et al.*, 2007; Ogilvie *et al.*, 2007). In addition, the roles, responsibilities and job titles of lay people delivering these interventions vary widely; however, they are generally understood to be either people selected by the community, resident in the community or part of the community (Walt, 1988).

Foster *et al.* (2007) reviewed the effectiveness of lay-led, self-management education programmes for people with chronic conditions in a general population. While they concluded that these programmes led to small short-term improvements in participants' self-efficacy, self-rated health and cognitive symptom management, these improvements were not clinically significant. There was no evidence for improved physiological health or health related quality of life (Foster *et al.* 2007). The Foster *et al.* (2007) review did not report on the effectiveness of programmes for minority-ethnic populations.

This systematic review reports the results of the effectiveness of lay-led group-based self-management interventions for minority-ethnic populations with cardiovascular disease or diabetes residing within high income 'developed' countries (Human Development Report, United Nations, 2010). The components of cultural adaptation in self-management interventions are described. This review was conducted as part of research team (Professor Kate Jolly [KJ], Dr Nicola Gale [NG], Dr Paramjit Gill [PG] and Dr Tom Marshall [TM]). I conducted systematic searches, independently read abstracts for inclusion (in duplicate with KJ) and conducted data extraction along with KJ, NG and PG. TM reviewed the final draft of the systematic review and provided comments.

3.2 REVIEW AIM AND OBJECTIVES

The aim of this systematic review was to assess lay-led, group-based, self-management interventions for minority-ethnic populations diagnosed with DM and/or CVD in relation to improving cognitive and clinical outcomes. The objectives were to:

- determine the effectiveness of interventions in improving behavioural and physiological outcomes for minority-ethnic participants;
- identify and describe components of culturally adapted lay-led group-based self-management interventions that are of value for minority-ethnic populations residing in high income countries, and
- develop a taxonomy of culturally adapted modifications used in self-management interventions for minority-ethnic populations.

3.3 METHODS

3.3.1 Inclusion Criteria

This review followed standard guidelines detailed in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins and Green, 2011). Studies that were included were of lay-led, group-based self-management interventions for people with types 1 and 2 diabetes mellitus (T1DM & T2DM) and CVD, that were culturally adapted for minority populations and who were currently residing in developed countries (using the Human Development Index, 2010) (Human Development Report, United Nations, 2010). Only papers researching DM and CVD were included as these are the most prevalent chronic conditions in minority-ethnic populations with global incidence rates continuing to rise. Lay support was defined as the absence of a professional qualification, such as nursing, dietetics, medicine, teaching or social work.

The clinical outcome measurements included fasting blood glucose, glycosylated haemoglobin (HbA1c), systolic and diastolic blood pressure, body mass index (BMI) and quality of life. Self-management outcome measures included cognitive measures (including

knowledge, self-efficacy), self-reported change in physical activity levels, smoking cessation and diet.

Only experimental studies (randomised controlled trials (RCTs), non-randomised controlled trials or before-and-after studies) were included, and those written in English. Articles were excluded if the sample contained participants aged less than 18 years, if the intervention was not delivered in a community or primary care setting or not culturally adapted for a minority group, or if the study was conducted in a developing country. Studies were also excluded if interventions were designed for populations that were at high risk and/or had shown symptoms of developing chronic conditions (e.g. pre-diabetes or obesity) rather than those with an established diagnosis of DM or CVD. The control group could have received standard medical treatment, a one-to-one intervention or an intervention by health care practitioners, or they could be on a waiting list for the intervention. Table 4 summarises the inclusion criteria for the review.

Table 4. Inclusion criteria for systematic review

Study Design	Randomised controlled trials, non-randomised studies, and before-and-after studies.
Population	Patients with diabetes mellitus (Types 1 or 2) or cardiovascular disease (or predominance of patients with these conditions, all other conditions are excluded) At least 40% of the sample comprised of individuals from minority-ethnic groups All participants in the sample over the age of 18 years
Intervention	Intervention should be predominantly delivered by an individual who is not a health care professional Delivered in primary care or community setting Study should be conducted in developed country (Use of Human Development Index 2010 Report, only studies conducted in ‘very high human development countries’) Group-based- at least 50% of activity delivered on the intervention should be group education Intervention should be culturally adapted for minority ethnic groups
Comparator(s)	Standard medical treatment One-to-one interventions Interventions delivered by health care professionals No treatment (or waiting list)
Outcome	Primary Outcome Measures: <ul style="list-style-type: none">- Cognitive measures (inc. knowledge, self-efficacy)- BMI (kg/m²)- HbA1c levels- Systolic and diastolic blood pressure- Reported change in patient physical activity levels Secondary Outcome Measures: <ul style="list-style-type: none">- Smoking cessation- Reported dietary modification- Adherence to programme/intervention

3.3.2 Search Methods

Electronic databases, including MEDLINE, EMBASE, CINAHL, ISI Web of Knowledge, Science Direct, Sociological Abstracts, and the Cochrane Central Register of Controlled Trials (CENTRAL) were searched for relevant studies from articles published in English only between January 1948 (or inception) and March 2011. Reference lists of retrieved articles were manually searched. The search for unpublished studies included NHS Evidence website, Department of Health UK website and any studies known to researchers that may fit the inclusion criteria. Some authors, of papers that could have been potentially included in this review, were contacted for further clarification. These authors were also asked to provide details of any studies, published or unpublished, they were aware of and could be included in this review. The high number of articles (198) identified was as a result of a literature review (Chapter 2) conducted on self-management programmes prior to this systematic review. However, the majority of these articles were duplicates of those found by systematic searching. Reference Manager (Version 11) was used to store and manage search results (Appendix 2 shows the electronic search strategy for one database).

Study selection is presented using a PRISMA template (Higgins and Green, 2011). KJ and I independently screened citations and abstracts to identify articles that might meet the inclusion criteria. Full text articles were retrieved and KJ and I independently determined whether they met the inclusion criteria. Uncertainty was resolved by consulting another member of the research team (PG).

3.3.3 Data Extraction and risk of bias assessment

Data extraction was undertaken independently by two reviewers (MS and either KJ, PG or NG). Disagreements were resolved through discussion. Interventions were systematically described using the Abraham and Michie (2008) categorisation of behavioural components of an intervention, as well as the type of lay person delivering it, components of the intervention, the number of sessions delivered and how it was tailored for members of minority-ethnic populations (Davidson *et al.*, 2003).

Risk of bias in RCTs was assessed by the same two reviewers documenting the quality of random sequence generation and allocation concealment, description of withdrawals and dropouts, blinded outcome assessment, and selective outcome reporting. To assess the methodological quality of single group and comparative before-and-after interventions, we referred to the Centre for Reviews and Dissemination handbook, using methods assessing methodological quality of case series studies (Khan *et al.*, 2001) and uncontrolled studies (Kidney *et al.*, 2009). Methodological quality assessment was based on four categories: selection bias (the generation of the sample with regards to recruitment and whether the sample is representative of the population at study); performance bias (ensuring all participants that accessed the intervention received a similar service and were treated equally); measurement bias (refers to the reporting of outcome measures and whether enough time was allocated at data collection intervals to observe a change in pre- and post-intervention scores), and attrition bias (the reporting of follow-up data with a complete description of withdrawals within groups).

3.3.4 Data synthesis

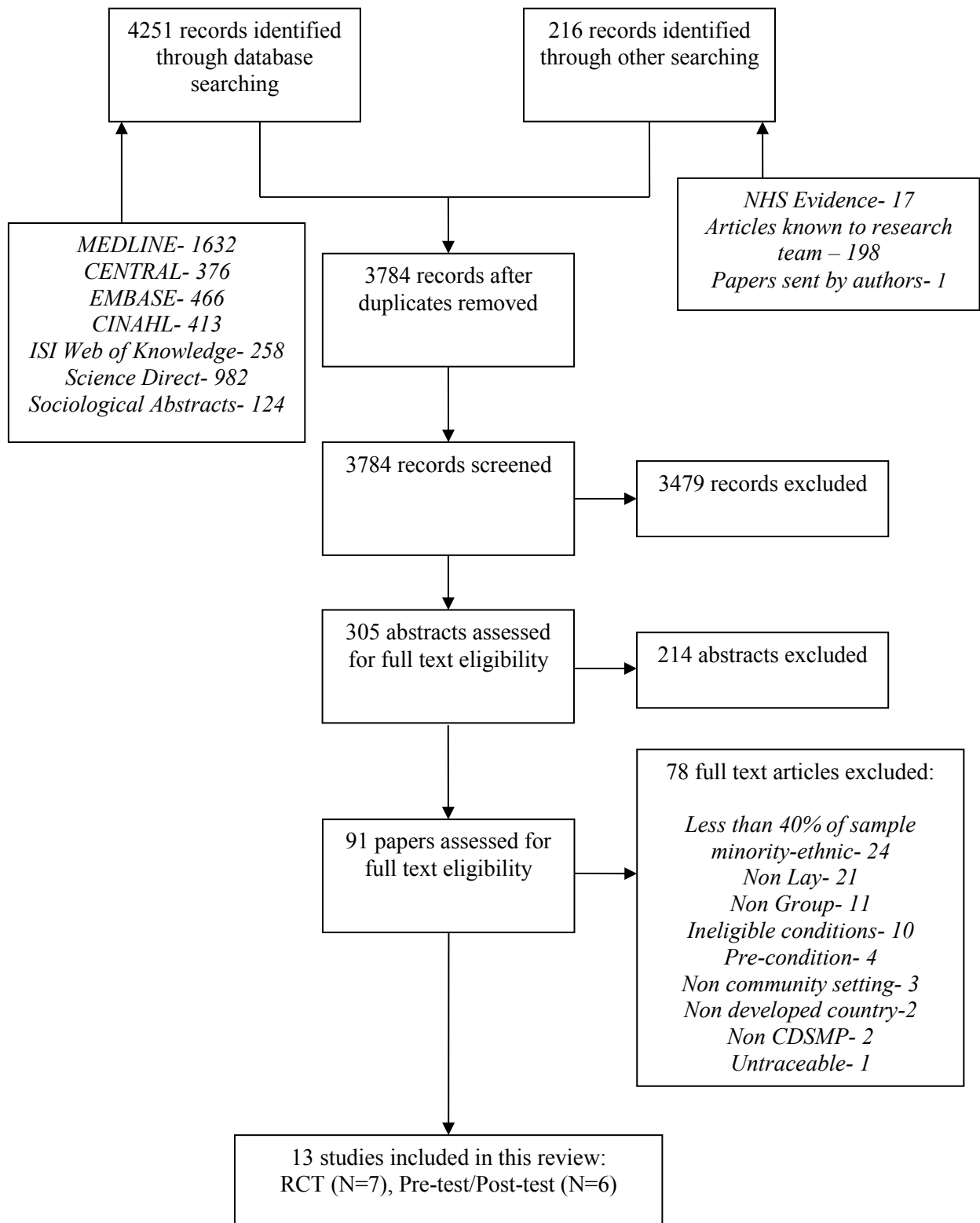
Data are presented narratively in tables (see Table 5). The interventions were assessed with regards to generating a positive outcome that was statistically significant ($p < 0.05$). The analytical approach in this review is descriptive and explanatory rather than quantitative. Meta-analysis was only possible for cognitive outcomes with a small number of studies.

3.4 RESULTS

3.4.1 Identification of the literature

The search identified 4467 citations. A number of citations were duplicates ($N=683$) and were excluded. 305 potentially relevant abstracts and 91 full-text articles were assessed for inclusion. Fourteen (reporting 13 trials) were eligible, and included in the review (figure 4).

Figure 4: Identification of relevant literature on group lay support for chronic disease self-management in minority-ethnic groups



3.4.2 Description of studies

The description of studies has been separated by self-management intervention type i.e. interventions described as chronic disease self-management programmes (Gitlen *et al.*, 2008; Griffiths *et al.*, 2005; Lorig *et al.*, 2003; 2005; 2008; Swerissen *et al.*, 2006; Tomioka *et al.*, 2011) and non-chronic disease self-management programmes (Castillo *et al.*, 2010; Choudhury *et al.*, 2009; Lujan *et al.*, 2007; McEwen *et al.*, 2010; Sixta and Ostwald *et al.*, 2008; Vincent *et al.*, 2007; 2009). Studies have been separated by intervention type to distinguish findings by studies which follow the scripted versions of the Stanford Model compared to those which have developed their own programme design. The characteristics of included studies appear in Table 5.

Table 5. Characteristics of studies/participants included in systematic review

Study (authors/location)	Design/Participants	Intervention	Outcome measures	Main findings
Castillo et al (2010) Chicago, United States	Single group pre-test/post-test design N=108 Hispanic/Latino participants with T2DM (n=70) Mean age 58.2 years 75.7% of Hispanic/Latino participants were female. F/U 10 weeks (post-intervention)	10 weekly sessions lasting 2 hours each in community venues, covering diabetes self-management education, delivered in Spanish by community health workers who had received 20 hours training; Behavioural change components: 1,2,4,8,9,10,19 Empowerment theory	Clinical: weight, HbA1c, blood pressure; Diabetes knowledge, self-care behaviours, empowerment; Depression (PHQ-9)	<u>Change from baseline to follow-up</u> Diabetes knowledge increased from 68.8% to 86.4% (p<0.001); HbA1c mean (sd) reduced from 8.38 (1.96) to 7.79 (1.67) (p=0.001 with ITT); Depression reduced from mean (sd) 8.15 (6.16) to 6.2 (5.73), p=0.04 (p=0.07 with ITT). Programme attrition: 33%
Choudhury et al (2009) Wales, United Kingdom	Single group pre-test/post-test design N=42 (28 women) Bangladeshi population with T2DM; average duration of disease 6.7 years. F/U 1 month post-intervention	Culturally adapted version of X-PERT Programme. One 4-hour group session delivered in Sylheti with dietary and exercise advice adapted for south Asian patients. Behavioural change components: 1,2,4,5,8, 9,19,20 Empowerment theory	Summary of Diabetes Self Care Activities (SDSCA) questionnaire (general diet, specific diet, exercise and foot care).	<u>Change from baseline to follow-up</u> General diet: increased 0.3 days (95% CI -0.1, 0.7) Specific diet: increase do.3 days (95% CI -0.2, 0.8) Exercise: increased 0.1 days (95% CI -0.7, 0.8) Foot care: 0.1 days(95% CI -0.9, 0.6)

Gitlen et al (2008) Philadelphia, United States	<p>Single group pre-test/post-test design</p> <p>N=519; 80% (N=414) completed post-test evaluations.</p> <p>African-American population with multiple chronic diseases (>70% with cardiovascular disease)</p> <p>Mean age 73.1 years, 86% female, 59.4% reported at least 3 chronic diseases</p> <p>F/U 4 months</p>	<p>CDSMP based on Lorig et al (1999) using biblical logo, culturally appropriate language, music and how to communicate with a health provider of a different race.</p> <p>6 weekly 3-hour sessions in community health centre, senior housing centre and church, led by African American peers;</p> <p>Behavioural change components: 1,8,9,10, 14,19,20,24</p> <p>Bandura's (1977) theory of self-efficacy</p>	<p>Physical activity; cognitive symptom ;communication with physician; health status; health care utilisation; self-efficacy; illness intrusiveness.</p> <p>Scales developed by Stanford Chronic Disease Self-Management Study (physical activity scale, diet, communication, self-efficacy).</p>	<p><u>Mean change (SD) from baseline to follow-up:</u></p> <p>Exercise score: 1.3 (3.3), p=0.001</p> <p>Self-efficacy: 0.6 (2.0) p=0.001</p> <p>Communication with Dr : 0.1 (1.3) n.s</p> <p>Self-rated health: 0.1 (0.7) n.s</p> <p>Disability: 0 (0.2) n.s</p> <p>Social role function: -0.1 (0.8) p=0.002</p> <p>Energy: -0.1 (0.8) p=0.001</p> <p>Health distress: -0.1 (0.9) p=0.001</p> <p>444 (85%) attended at least 4/6 sessions</p>
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Griffiths et al (2005) London, United Kingdom	<p>RCT</p> <p>N=476 (int: 238; control 238)</p> <p>Bangladeshi participants with multiple chronic diseases (>70% with diabetes &/or cardiovascular disease)</p> <p>Mean age 49 years; 57.1% female.</p> <p>F/U 4 months</p>	<p>CDSMP based on Lorig et al (1999) adapted for Islamic culture and delivered in Sylheti to single sex groups with Bangladeshi lay tutors of same sex, who also suffered from chronic disease.</p> <p>6 weekly 3-hour sessions in general practices and community venues.</p> <p>Behavioural change components: 1,4,8,9,11, 12,13,24</p> <p>Bandura's (1977) theory of self-efficacy</p>	<p>Primary outcomes: Chronic Disease Self-efficacy Scale (general condition, distress, non medication, fatigue, discomfort and interference).</p> <p>Self-management behaviours, communication with physician, health status (depression, pain, anxiety, fatigue and shortness of breath), and healthcare use.</p> <p>Hospital Anxiety and Depression Scale, EuroQol EQ5D.</p>	<p><u>Between group adjusted differences in means at 4 months</u></p> <p>Self-efficacy: 0.67 (95% CI 0.08 to 1.25)</p> <p>Self-care behaviour 0.53 (95% CI 0.01 to 1.06)</p> <p>There were small non-significant improvements for int. group for all other outcome measures.</p> <p>For those completing 3 or more sessions (N=121), statistically significant scores were achieved for self-efficacy, self-care behaviour and depression.</p>
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Lorig et al (2003) California, United States	<p>RCT</p> <p>N=551 (int: 327; 4-month waiting list control: 224)</p> <p>Hispanic (Spanish speakers) with multiple chronic diseases (>40% diabetes &/or cardiovascular disease)</p> <p>Mean age 57 years; 79% female; 94% foreign born.</p> <p>F/U 4 months and 12 months</p>	<p>Tomando intervention delivered in Spanish by two peer leaders. Included: healthy eating, exercise, action planning, cognitive management, self-talk, medication, depression, working with healthcare providers, treatment decisions and planning for the future. Particular focus on healthy eating and family communications. Used culturally appropriate exercise and relaxation audiotape.</p> <p>6 weekly 2 1/2 hour sessions in community venues.</p> <p>Behavioural change components: 1,5,8,9,10,24</p> <p>Bandura's (1977) theory of self-efficacy</p>	<p>Health behaviours (physical activity scale, strength, aerobic exercise, diet and relaxation); communication with physicians; health status (self-rated health) pain, fatigue); self-efficacy and health care use (visits to physicians, emergency departments and days in hospital over the past 4 months.</p> <p>Scales developed by Stanford Chronic Disease Self-management Study; Health Status scale from the Medical Outcomes Study, Marin Short Acculturation Scale.</p>	<p><u>4 months: change from baseline:</u></p> <p>Exercise mins (sd): int: 63.7 (172); con: 31.0 (132) p=0.001; Effect size (of mean difference) 0.28</p> <p>Communication with Dr: Int:0.7 (1.65), con: 0.22 (1.51) p<0.001; Effect size 0.34</p> <p>Stress management/week: int: 0.83 (2.4), con:-0.21 (1.78), p<0.00; Effect size (0.71)</p> <p>Emergency room visits/4-months: int: -0.08 (0.62), con:0.10, p=0.005; Effect size - 0.29</p> <p>Self-efficacy: int: 1.16 (3.1), con:0.72 (3.1), p<0.001; Effect size (0.16)</p> <p><u>12 months:</u></p> <p>Exercise mins (sd) base: 103 (104); 12m: 59 (148) p<0.001</p> <p>Communication with Dr: base:1.73 (1.4), 12m: 0.73 (1.7) p<0.001</p> <p>Stress management/week: base:</p>
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				0.38 (1.4), 12m:0.62(2.5), p<0.001
				Emergency room visits/4- months: base: 0.27 (0.7), 12m:-0.12, p<0.01
				Self-efficacy: base: 0.30 (2.5), 12m: -0.05 (1.7), n.s
Lorig et al (2005) El Paso, United States	Single group pre-test/post- test design N=445 Hispanic/Latino (Spanish n=319) and English speaking population with multiple chronic diseases (>60% with diabetes) Mean age 61.3 years, 83% female F/U 4 months and 12 months	As Lorig (2003) Behavioural change components: 1,5,8,10,13,24	Health behaviours (physical activity scale, strength, aerobic exercise, diet and relaxation); communication with physicians; health status; self-efficacy and health care use (visits to physicians, emergency departments and days in hospital over the past 4 months. Scales developed by Stanford Chronic Disease Self- management Study; Health Status scale from the Medical Outcomes Study	Spanish sample: change from baseline to <u>4-months</u> (mean (sd): Exercise: 47.4 mins (144), p<0.001 Communication with Dr: 0.04 (1.4) n.s Stress management/week: 0.97 (2.8) p<0.001 Physician visits/4-months: 0.34 (2.1) p=0.01 Self-efficacy: 1.76 (3.0) p<0.001 At <u>12 months</u> there were significant improvements in the Spanish speaking sample in: times breakfast eaten, stress management, exercise, activity limitation, health distress, self- reported health, self-efficacy and days in hospital. Mean sessions attended 4.9

Lorig et al (2008)	RCT	As Lorig (2003)	Health indicators: HbA1c, self-reported health, limitation, fatigue, symptoms of hypoglycaemia.	<u>6 months: change from baseline</u>
San Francisco, United States	N=533 (int only: 219; int with telephone reinforcement: 116; con: 198)	Behavioural change components: 1,4,8,10,13,19,24	Health behaviours (aerobic exercise, strength, communication with physician, glucose testing).	HbA1c: int: -0.41 (1.4); con: -0.05 (1.6) p=0.04
	Hispanic/Latino (Spanish speakers) T2DM		Health status.	Health distress: int: -0.60 (1.3); con: -0.09 (1.3) p=0.009
	Mean age 52.9 years; 259 (62%) female; 302 (72.5%) born in Mexico		Self-efficacy.	Symptoms of hypoglycaemia: int: -0.45 (1.8); con: 0.03 (1.5) p=0.04
	F/U 6 months and 18 months		Health care use: visits to physicians, emergency departments and days in hospital over the past 6 months.	Symptoms of hyperglycaemia: int: -0.83 (2.1); con: 0.03 (2.1) p<0.001
			Scales developed by Stanford Chronic Disease Self-management Study; Health Status scale from the Medical Outcomes Study	No significant differences in global health, activity limitation, fatigue, exercise, communication with Dr, health care utilisation.
				Self-efficacy: int: 0.70 (2.4), con: 0.00 (2.4) p<0.01

Lujan et al (2007)	RCT	Promotora Diabetes Intervention delivered in Spanish and English. Content focused on illness related care, individuals were encouraged to share experiences with Promotoras who had received 60 hours training on diabetes self-management.	Acculturation (US/Mexican culture), glycaemic control, diabetes knowledge and health beliefs	<u>6 months: change from baseline</u>
Texas-Mexico border, United States	N=149 (int: 75; con: 74) Mexican American population with T2DM F/U 3 and 6 months	6 month intervention: 8 x weekly group sessions lasting 2 hours each, 4 telephone contacts and 8 behaviour change postcards. Behavioural change components: 1, 2, 4, 8, 9, 11, 18, 19 A middle range theory of community empowerment	Deyo 4 item acculturation scale, diabetes knowledge questionnaire, diabetes health belief management questionnaire	A1c: decrease in int. group; increase in con. group Diabetes knowledge: mean score change higher in int. group (p<0.05) Health beliefs: decrease less in int. group compared to con. group (p<0.01)

McEwen et al (2010)	Single group pre-test/ post-test design	Intervention delivered in Spanish with Promotoras with basic knowledge of diabetes and facilitating groups. Content based on T2DM, physical activity, self-management skills, social support, nutrition and distress management	Behavioural outcomes (nutrition, physical activity, diabetes distress); diabetes knowledge; Physiological measures (HbA1c, BMI).	<u>6 months: change from pre to post intervention:</u>
US/Mexico border region, United States	N=21 Mexican American population (Spanish speaking) with T2DM Mean age 53.71 years; 17 female; mean duration with T2DM 7.2 years	6 monthly 2 hour group sessions delivered in Catholic Church; 3 individually tailored sessions lasting 60-90 mins in participant's home Behavioural change components: 1, 2, 6, 8, 12, 14, 19 Not based on a particular behavioural change theory	Summary of Diabetes Self Care Activities (SDSCA), International Physical Activity Questionnaire (IPAQ), Diabetes Distress Scale, Diabetes Knowledge Questionnaire	Mean change from pre to post intervention Diet: 0.99 (95% CI -2.0, 0.02) increase in nutritional intake (p<0.05); effect size 0.41 Exercise: 1.42 exercise self-care (95% CI -2.62, -0.24) score; effect size 0.54 (p<0.05); minutes spent sitting decreased 96 minutes (95% CI 20, 172) (p<0.05); effect size 0.58 Total diabetes distress: decrease in diabetes distress -2.09 95% CI -0.56, 4.75) n.s; effect size 0.36 Diabetes knowledge: increase score 1.28 (95% CI -2.58, 0.01) (P<0.05); effect size 0.45 Physiological measures: non significant change, pre to post intervention, in HbA1c : 0.12% (95% CI -0.85, 0.60); effect size 0.08, and BMI: -0.12 (95% CI -0.41, 0.65); effect size 0.10

Sixta and Ostwald (2008)	RCT	Intervention delivered in Spanish with two Promotoras extensively using visual aids. Content related to information about disease, emotions, complications, blood glucose levels, exercise and nutrition, multi-disciplinary medical appointments and coping strategies.	Health beliefs, Diabetes knowledge, HbA1c, and Acculturation.	<u>6 months: change from baseline</u>
Texas-Mexico border, United States	N=131 (int: 63; con: 68)	10 x weekly sessions lasting 90 mins each delivered in community clinic	Health Belief Questionnaire (25 item scale); Diabetes Knowledge Questionnaire (24 item); Acculturation (0-4)	HbA1c: no significant change between int. and con. group.
	Mexican American population with T2DM	Behavioural change components: 1, 2, 4, 5, 8, 10, 11, 13, 19, 24		Diabetes knowledge: increase in diabetes knowledge in int. group which was significantly affected greater than control group (p<0.05)
	Age ranged from 26-81 years; 71% female; mean duration with T2DM 6.8 years	Not based on a particular behavioural change theory		Health beliefs: no change in health beliefs at six months
	F/U 3 and 6 months			

Swerissen et al (2006) State of Victoria, Australia	<p>RCT</p> <p>N=728 (completed study: 474; int. 320; con: 154)</p> <p>Italian, Greek, Vietnamese, and Chinese population with multiple chronic conditions (>40% with diabetes and/or CVD)</p> <p>F/U 6 months</p>	<p>CDSMP based on Lorig et al (1999) delivered in Chinese, Italian, Greek and Vietnamese, by a pair of trained bi-lingual peer leaders who had received 20 hours training. Participants provided audio cassette and programme booklet in their first language.</p> <p>6 weekly sessions lasting 2 hours and 30 mins each at community based venues.</p> <p>Behavioural change components: 1, 4, 6, 9, 11, 13, 24</p> <p>Bandura's (1977) theoretical model of self-efficacy</p>	<p>Health behaviours (physical activity scale, strength, aerobic exercise, diet and relaxation); communication with physicians; health status; self-efficacy and health care use (visits to physicians, emergency departments and days in hospital over the past 6 months).</p> <p>Scales developed by Stanford Chronic Disease Self-management Study; Health Status scale from the Medical Outcomes Study</p>	<p><u>Between group differences at 6 months:</u></p> <p>Exercise: int. groups exercised more frequently (p=0.005)</p> <p>Self-efficacy: int 7.29; con 6.13 (p<0.001)</p> <p>Health status better in int. group:</p> <p>Energy: int. 2.13; con 1.87 (p<0.001)</p> <p>Self-rated health: : int. 3.5; con 3.81 (p<0.001)</p> <p>Health distress: int 1.29; con 1.5 (p=0.04)</p> <p>Fatigue: int 3.94; con 4.54 (p=0.01)</p> <p>Pain: int 3.69; con 4.69 (p=0.001)</p> <p>No significant improvement, in comparison to con. groups in disability, social role, illness intrusiveness, depression, shortness of breath or health care utilisation.</p>
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<p>Tomioka et al (2011)</p> <p>Hawaii, United States</p>	<p>Comparative pre-test/post-test design</p> <p>N=675 (baseline and six month data available for 422 participants)</p> <p>Asian (Japanese, Chinese, Korean, Filipino) and Pacific Islanders with multiple chronic conditions (>40% with diabetes and/or CVD)</p> <p>Mean age 71.92 years, 85.6% female</p> <p>F/U 6 months</p>	<p>CDSMP based on Lorig et al (1999) adapted for Hawaiian population: local name; culturally relevant logo, inclusion of prayer and local food. Delivered in English by CDSMP leaders who had received 14 training sessions by individuals from Stanford University.</p> <p>6 weekly sessions lasting 2 hours and 30 mins each delivered in community based locations.</p> <p>Behavioural change components: 4, 6, 8, 17, 19, 24</p> <p>Bandura's (1977) theoretical model of self-efficacy</p>	<p>Health behaviours (physical activity scale, strength, aerobic exercise, diet and relaxation); communication with physicians; health status; self-efficacy and health care use (visits to physicians, emergency departments and days in hospital over the past 6 months).</p> <p>Scales developed by Stanford Chronic Disease Self-management Study; Health Status scale from the Medical Outcomes Study</p>	<p><u>6 months: change from baseline</u></p> <p>Social role activities: All groups showed improvement ($p<0.05$)</p> <p>Health care use: increase in communication with physicians (all groups)</p> <p>Self-rated health: increase for Asians Pacific Islanders ($p<0.05$)</p> <p>Exercise: increase for Asians Pacific Islanders ($p<0.05$) for stretching and strengthening exercises. Asians showed increase in time spent in aerobic exercise.</p> <p>Physical abilities: Caucasians and Asians showed reduction in limitations ($p<0.05$)</p> <p>Self-efficacy: Asians showed significant increase ($p<0.001$)</p>
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Vincent et al (2007; 2009) Arizona, United States	RCT N=20 (17 participants included in analysis) Mexican American population with T2DM Mean age 56 years, mean years with T2DM 7.9 years, 71% female F/U post intervention (8 weeks) and 3 months	Intervention based on National Diabetes Education Program and American Diabetes Association (ADA) guidelines: information on disease management and complications, diet, exercise and self-monitoring. Delivered in Spanish by Promotoras with emphasis on culturally relevant advice: home remedies and ethnic foods. 8 weekly sessions lasting 2 hours each Behavioural change components: 1, 2, 8, 9, 19, 20, 24 Bandura's (1977) theoretical model of self-efficacy	Diabetes knowledge; self- efficacy; blood glucose (mg/dl) HbA1c; weight (lbs); body mass index self-management activities; diet; exercise; blood glucose testing; foot care; medications Diabetes Knowledge Questionnaire, Self-Efficacy for Diabetes Scale, Summary of Diabetes Self Care Activities, Short Acculturation Scale for Hispanics (SASH)	<u>Between group differences at 3 months:</u> Diabetes knowledge: effect size (group by time interaction) 0.36, n.s Weight: effect size 0.39, n.s BMI: effect size 0.39, n.s Blood glucose: effect size 0.26, n.s Significant improvements in weight, BMI and blood glucose for the int. group post intervention.
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Base: baseline; Con: control group; Int: intervention group; ITT: intention to treat; N.S: non-significant; T2DM: type 2 diabetes.
Confidence intervals and effect sizes have been reported where available.

*Abraham and Michie (2008) Taxonomy of behaviour change techniques:

1. Provide general information on behaviour-health link; 2. Provide information on consequences; 3. Provide information about others' approval; 4. Prompt intention formation; 5. Prompt barrier identification; 6. Provide general encouragement; 7. Set graded tasks; 8. Provide instruction; 9. Model/Demonstrate the behaviour; 10. Prompt specific goal setting; 11. Prompt review of behavioural goals; 12. Prompt self-monitoring of behaviour; 13. Provide feedback on performance; 14. Provide contingent rewards; 15. Teach to use prompts/cues; 16. Agree behavioural contract; 17. Prompt practice; 18. Use of follow-up prompts; 19. Provide opportunities for social comparison; 20. Plan social support/social change; 21. Prompt identification as role model/position advocate; 22. Prompt self-talk; 23. Relapse prevention; 24. Stress management; 25. Motivational interviewing; 26. Time management

3.4.2.1 Background on self-management interventions: CDSMPs

A single study was delivered in the UK to the Bangladeshi population (Griffiths *et al.*, 2005), another in Australia to Vietnamese, Chinese, Italian and Greek populations (Swerissen *et al.*, 2006), with the remainder delivered in the US to Hispanic and/or Latino (Lorig *et al.*, 2003; 2005; 2008), African American (Gitlen *et al.*, 2008), Asian (Japanese, Chinese, Korean or Filipino) and Pacific Islander populations (Tomioka *et al.*, 2011). Four studies were RCTs (Griffiths *et al.*, 2005; Lorig *et al.*, 2003; 2008; Swerissen *et al.*, 2006) two studies were comparative pre-test post-test designs (Lorig *et al.*, 2005; Tomioka *et al.*, 2011) and one a single pre-test post-test design (Gitlen *et al.*, 2008).

Six studies were conducted with populations suffering from T2DM and CVD (Gitlen *et al.*, 2008; Griffiths *et al.*, 2005; Lorig *et al.*, 2003; 2005; Swerissen *et al.*, 2006; Tomioka *et al.*, 2011) with one study with patients suffering with T2DM only. All of the studies used peers to deliver the intervention, apart from Griffiths *et al.* (2008) who used lay tutors.

3.4.2.2 Background on self-management interventions: Non-CDSMPs

A single study was delivered in the UK to the Bangladeshi population (Choudhury *et al.*, 2009), while the remaining studies were delivered in the U.S. with the Mexican American population (Lujan *et al.*, 2007; McEwen *et al.*, 2010; Sixta and Ostwald *et al.*, 2008; Vincent *et al.*, 2007; 2009) and Hispanic population (Castillo *et al.*, 2010). Three studies were RCTs (Lujan *et al.*, 2007; Sixta and Ostwald, 2008; Vincent *et al.*, 2007; 2009) and three were single pre-test post-test designs (Castillo *et al.*, 2010; Choudhury *et al.*, 2009; McEwen *et al.*, 2010). One study was conducted with individuals suffering with T2DM and CVD

(Choudhury *et al.*, 2009), with the remaining studies specific to populations suffering from T2DM.

In four studies the intervention was delivered by Mexican community Health Workers ('Promotoras') (Lujan *et al.*, 2007; McEwen *et al.*, 2010; Sixta and Ostwald, 2008; Vincent *et al.*, 2007; 2009); Castillo *et al.* (2010) used community health workers, and Choudhury *et al.* (2009) used peers.

3.4.2.3 Cultural adaptation

Two studies did not deliver CDSMPs in minority-ethnic languages (Gitlin *et al.*, 2008; Tomioka *et al.*, 2011). Gitlin *et al.* (2008) and Tomioka *et al.* (2011) included a biblical logo that represented health and spirituality along with moments of prayer/silence at the beginning of each session. Lorig *et al.* (2003) encouraged participants to bring family members along. All studies modified content so it was applicable to cultural diets/foods.

Acculturation, the extent a migrant population have assimilated to the cultural beliefs and values of the host country, was measured in three non-CDSMP studies, all in Mexican American populations in the US (Lujan *et al.*, 2007; Sixta and Ostwald, 2008; Vincent *et al.*, 2007; 2008). Choudhury *et al.* (2009) culturally adapted their intervention for single sex groups with appropriate same-sex lay tutors. Non-CDSMPs detailed greater numbers of cultural adaptations, particularly the inclusion of religious/spiritual modifications (Lujan *et al.*, 2007) and cultural measures such as inviting family and friends (Lujan *et al.*, 2007; Vincent *et al.*, 2007; 2009). All studies were delivered in a minority-ethnic language.

3.4.2.4 Theoretical basis of studies

Interventions used an array of methods and techniques to encourage behavioural change. The majority involved didactic and interactive sessions, use of action plans and feedback, problem solving and positive self-talk i.e. encouraging a person to talk to themselves (aloud or silently) before and during planned behaviours to encourage and support action (Abraham and Michie, 2008). Bandura's (1977) self-efficacy theory or social learning theory (part of social cognitive theory) was used in all seven studies of CDSMPs (Gitlen *et al.*, 2008; Griffiths *et al.*, 2005; Lorig *et al.*, 2003; 2005; 2008; Swerissen *et al.*, 2006; Tomioka *et al.*, 2011) and one non-CDSMP (Vincent *et al.*, 2007; 2009). The remaining five non-CDSMPs were based on some form of empowerment theory (Castillo *et al.*, 2010; Choudhury *et al.*, 2009; Lujan *et al.*, 2007) or did not state an explicit theoretical or behavioural change framework (McEwen *et al.*, 2010; Sixta and Ostwald, 2008).

Interventions included a range of behaviour change techniques that reflected a variety of theoretical positions (Abraham and Michie, 2008). All studies emphasised emotional well-being, relaxation or stress/anxiety management. Some studies (Griffiths *et al.*, 2005; Lorig *et al.*, 2005; Lujan *et al.*, 2007) explicitly stated they used self-talk and the technique of stress management. The majority of the interventions included some techniques associated with social cognitive theory, such as prompting intention formation i.e. encouraging the person to set a general goal or make a behavioural resolution e.g. 'I will take more exercise next week' (Abraham and Michie, 2008), information on consequences of a behaviour and demonstration of a behaviour. Several also included self-monitoring (a person is asked to keep a record or diary of specified behaviour[s]) and social comparison techniques (participants in a group supporting each other).

3.4.3 Risk of bias in included studies

3.4.3.1 Randomised controlled trials

Table 6 summarises the methodological quality and risk of bias for the RCTs. Only two RCTs (Griffiths *et al.*, 2005; Vincent *et al.*, 2007; 2009) explicitly stated the randomisation process, details regarding allocation concealment and/or blinding were either poorly described or not provided. One study explicitly stated that there was potential for an ‘attention effect’ (Lorig *et al.*, 2008) as participants could not be blinded. Three studies (Lujan *et al.*, 2007; Swerissen *et al.*, 2006; Vincent *et al.*, 2007; 2009) provided a complete description of drop outs and withdrawals; while the remaining studies failed to provide a clear process of how their sample became reduced or altered at each follow-up period.

3.4.3.2 Uncontrolled before-and-after and non-randomised studies

Table 7 reports the methodological quality and risk of bias for the non-RCTs. All six studies had considerably more women than men in their sample. Furthermore, all studies recruited participants in a non-standardised manner, with one study (Choudhury *et al.*, 2009) stating the researcher used personal contacts to generate potential participants. Two studies (Castillo *et al.*, 2010; Choudhury *et al.*, 2009) stated groups were assigned according to gender or language proficiency without providing details on adjustments that were made to ensure each group received the same intervention.

With regards to measurement bias, three studies (Castillo *et al.*, 2010; Choudhury *et al.*, 2009; Lorig *et al.*, 2005) showed a potential high risk of bias due to greater reporting on specific sub-samples of their study, peer educators potentially influencing answers to questionnaires and not reporting on an outcome measure that was stated to be a part of a questionnaire

administered to participants. Details on drop outs were poorly reported in studies described as before-and-after interventions.

Table 6. Assessment of methodological quality and risk of bias (randomised controlled trials)

Author(s)	Random Generation of Sample	Allocation Concealment	Blinding Outcome Assessment	Incomplete Data (attrition bias)	Selective Reporting
Griffiths et al (2005)	Low risk of bias: “researcher who randomised them using a computer minimisation programme”	Low risk of bias: “using a computer minimisation programme.”	Low risk of bias: “Interviewers were blinded to treatment allocation”	Low risk of bias: Int: 221/238 F/U at 4 months Con: 218/238 F/U at 4 months Significant information on drop-outs	Unclear risk of bias
Lorig et al (2003)	Unclear risk of bias: “randomisation with a different ratio of intervention to control subjects was conducted”	Unclear risk of bias: “participants applied for Tomando at specific site”	Low risk of bias: “those delivering the intervention were not involved in outcome assessment	Low risk of bias: Int: 81% F/U at 4 months Con: 79% F/U at 4 months Significant information on drop-outs	Unclear risk of bias
Lorig et al (2008)	Unclear risk of bias: “most study participants were randomised to three groups”	Unclear risk of bias: No details provided on allocation or who was conducting allocation	Unclear risk of bias: Participants could not be blinded, there is a possibility of an attention effect	Unclear risk of bias: Int: 179/219 F/U at 6 months Con: 173/198 F/U at 6 months Lack of information provided on drop outs	Low risk of bias

Author(s)	Random Generation of sample	Allocation Concealment	Blinding Outcome Assessment	Incomplete data (attrition bias)	Selective Reporting
Lujan et al (2007)	Unclear risk of bias: 150 participants who met inclusion criteria were selected from a pool of 160 interested and eligible participants. The 150 were then randomised.	Unclear risk of bias: No details provided on allocation concealment	Low risk of bias: Outcome assessor blinded	Low risk of bias: 6% attrition rate with details of drop outs provided.	Unclear risk of bias
Swerissen et al (2006)	Unclear risk of bias: “Following stratification participants were randomly allocated to intervention or waiting list control groups.”	Unclear risk of bias: “Participants were stratified by language and the local government area they lived	Unclear risk of bias: Individual who conducted data collection not stated.	High risk of bias: 474/728 took part in study, unable to contact 85/254 lost to follow-up	Unclear risk of bias
Vincent et al (2007; 2009)	Low risk of bias: “randomly assigned to control or intervention group using a list of random numbers from the Microsoft Excel random-number generator function”	Unclear risk of bias: Participants attended an information session about the study- unsure whether this included details of both intervention and control arms	Low risk of bias: Those delivering the intervention were not involved in outcome assessment.	Low risk of bias: Full description provided on drop outs, little attrition bias F/U 17/20	Unclear risk of bias

Table 7. Assessment of methodological quality and risk of bias (before and after interventions)

Author(s)	Selection Bias (how sample was generated)	Performance Bias (confounding/ treatment of groups)	Measurement Bias (reporting of outcome measures)	Attrition Bias (incomplete follow-up data)
Castillo et al (2010)	High risk of bias: Fliers, posters, newspaper advertisements, health fairs and screening, schools, senior centres, YMCAs and community gatherings used to generate sample but no information on numbers generated from each method.	High risk of bias: Groups formed on the basis on language proficiency, and accordingly sessions were delivered in English or Spanish.	High risk of bias: All outcome measures reported apart from one- smoking- which was part of a 11 item SDSCA questionnaire.	High risk of bias: 23/70 lost at F/U but 3 returned and completed the programme. Unsure whether the 3 participants were part of data analysis.
Choudhury et al (2009)	High risk of bias: Recruitment conducted in a non-standardised manner using community based locations along with peer educators and author using personal contacts.	High risk of bias: Application of single gender group, therefore groups may have been treated different.	High risk of bias: Questionnaires completed with the help of peer educators by discussing the range of possible answers.	Unclear risk of bias: 72 patients registered to attend but only 42 attended- no description of remaining 30.
Gitlen et al (2008)	High risk of bias: Recruitment conducted in a non-standardised manner using community based locations and majority (75.9%) from single location (senior centre)	Low risk of bias: Significant information on treatment fidelity with independent representative conducting 34 observations. High level of uniformity across sessions.	Low risk of bias: All outcome measures reported on at pre-test and post-test for program completers.	Unclear risk of bias: 569 participants initially recruited, but only 519 enrolled- no description of 50 that did not enrol.

Author(s)	Selection Bias (how sample was generated)	Performance Bias (confounding/ treatment of groups)	Measurement Bias (reporting of outcome measures)	Attrition Bias (incomplete follow up data)
Lorig et al (2005)	High risk of bias: “Each program was advertised in the community where it was to be given by word of mouth, through clinics, and using the mass media” Sample contains higher percentage of women and those suffering from diabetes.	Unclear risk of bias: Participants still had contact with other healthcare services in-between data collection intervals- in particular physician visits	High risk of bias: Greater reporting was conducted on Spanish speaking sample at 1 year (in comparison to English speakers) and greater analysis on Spanish speakers with diabetes. Data collected at 4 month and 1 year.	Low risk of bias: “Four month questionnaires were completed by 82% of the Spanish speakers and 85% of the English speakers, while 77% of the eligible Spanish speakers completed 1-year questionnaires. No significant difference at baseline between dropouts and those completing 4 month data
McEwen et al (2010)	Unclear risk of bias: Approximately 500 individuals with Hispanic surnames and zip codes identified from attendance logs of the outreach program.	Low risk of bias: High level of fidelity- monthly supervisions by research team and reporting by promotora post course to the research team.	Unclear risk of bias: All outcome measures reported on pre and post intervention.	Unclear risk of bias: 5 of 21 participants completed all six monthly group sessions. Incomplete information on drop outs.
Tomioka et al (2011)	High risk of bias: Recruitment conducted in a non-standardised manner via community locations and medical organisations.	Low risk of bias: Fidelity information collected for 71 (99%) of all workshops by trained evaluators providing a written report to the lead evaluator.	Low risk of bias: All outcome measures reported on at pre-test and post-test for program completers.	Unclear risk of bias: 741 participants enrolled on CDSMP. 32 participants did not respond to demographic questions, 34 participants did not identify themselves as Caucasians or Asian Pacific Islanders. Data on attendance collected from 668/675 of participants. Unclear description of drop outs.

3.4.4 Effectiveness of interventions

The results are reported separately for interventions measuring between-group differences (Griffiths *et al.*, 2005; Lorig *et al.*, 2003; 2008; Lujan *et al.*, 2007; Sixta and Ostwald, 2008; Swerissen *et al.*, 2006; Vincent *et al.*, 2007; 2009) and interventions measuring within group differences (Castillo *et al.*, 2010; Gitlen *et al.*, 2008; Lorig *et al.*, 2005; Choudhury *et al.*, 2009; McEwen *et al.*, 2010; Tomioka *et al.*, 2011). The results have been summarised in Table 8.

3.4.4.1 Between group differences

Six of the RCTs reported the difference between the intervention and control group for change from baseline to follow-up. Swerissen *et al.* (2006) reported difference between groups at follow-up. Statistically significant differences favouring the intervention group were reported for four of the five trials for self-efficacy, all three RCTs reporting self-reported health and health distress, two out of three trials reporting pain and two of the four trials reporting fatigue, HbA1c and physical activity. At 18 months, one study reported that a statistically significant improvement in Hb1Ac had been maintained (Lorig *et al.*, 2008). No improvements were seen for depression (Griffiths *et al.*, 2005), activity limitation or BMI. Swerissen *et al.* (2006) reported that the Greek sub-sample reported a higher depression score than the control group post intervention ($P=0.048$), improvement in fatigue in the Chinese and Vietnamese sub-samples only (in comparison to control groups) and lower activity limitation with the Vietnamese sub-sample in comparison to the control group (mean -0.75, $P<0.05$) which was not present in any of the other sub-sample populations i.e. Chinese, Greek and Italian populations.

3.4.4.2 Studies measuring within group differences

Five of the six studies reported within group change for the whole samples, whereas Tomioka *et al.* (2011) presented results for individual ethnic sub-groups. Results are summarised in Table 8. Statistically significant improvements from baseline to follow-up were reported for two of three studies reporting self-efficacy, one of two studies for self-reported health and HbA1c, both studies reporting health distress and diabetes knowledge, one study reporting fatigue, three out of four studies reporting dietary modification and four of five studies reporting physical activity. BMI did not reduce in the one study reporting this. Tomioka *et al.* (2011) reported statistically significant improvement in self-efficacy for Caucasian and Asian participants, in self-reported health for Native Hawaiian and Pacific Islanders (NHPIs) and Asian participants, in health distress for Asian participants (MD -0.89, SD=1.29, $P<0.05$); Tomioka *et al.* (2011) in pain ($P<0.05$) for their Asian sub-sample and in activity limitation in all the ethnic sub-groups.

Table 8. Summary of results for studies included in review

Randomised Controlled Trials Difference in change from baseline to follow-up between intervention and control + favours intervention; x favours control; +/- no difference; blank – not reported							
<i>Author(s)</i>	Lorig et al 2003	Griffiths et al 2005	Lorig et al 2008	Lujan et al 2007	Sixta and Ostwald 2008	Vincent et al 2007; 2009	Swerissen et al 2006
<i>Primary Outcomes</i>							
Self-Efficacy	+	+	+			+/-	+
Self-Reported Health	+		+(18 months)				+
Health Distress	+		+				+
Depression/Anxiety		+/-					+/-
Pain	+	+/-					+
Fatigue	+	+/-	+/-				+
Activity Limitation			+/-				+/-
Diabetes Knowledge				+	+	+/-	
BMI						+/-	
Hb1Ac			+	+	+/-	+/-	
Physical Activity	+		+/-			+/-	+
<i>Secondary Outcomes</i>							
Smoking Cessation	+(1yr)						
Dietary Modification						+/-	

Single and comparative group pre-test post-test design Difference in change from baseline to post intervention + improvement (P<0.05); x no/ non-significant improvement; blank – not reported						
<i>Author(s)</i>	Lorig et al 2005	Choudhury et al 2009	Gitlen et al 2008	Castillo et al 2010	McEwen et al 2010	Tomiolka et al (2011)
Primary Outcomes						
Self-Efficacy	+		+	x		+ (Caucasians and Asians) x (NHPI)
Self-Reported Health	+		x			+ (Asians and NHPI) x (Caucasians)
Health Distress	+		+			+ (Caucasians and Asians) x (NHPI)
Depression/Anxiety						
Pain	+					+ (Asians) x (Caucasians and NHPI)
Fatigue	x		+			+ (Caucasians and Asians) x (NHPI)
Activity Limitation	+					+ (Caucasians, Asians and NHPI)
Diabetes Knowledge				+	+	
BMI					x	
Hb1Ac				+	x	
Physical Activity	+	x	+	+	+	+ (Caucasians, Asians and NHPI)
Secondary Outcomes						

Smoking Cessation						
Dietary Modification	+	✕		+	+	

NHPI: Native Hawaiian and Pacific Islanders

3.4.5 Adherence to Programme/ Intervention

Four studies reported the mean number of sessions completed (Lorig *et al.*, 2003; 2005; Swerissen *et al.*, 2006; Tomioka *et al.*, 2011), ranging from 4.3 to 5.2 out of six sessions. Tomioka *et al.* (2011) stated Asians in their sample completed a greater mean number of sessions in comparison to Caucasians and NHPIs. Lujan *et al.* (2007) reported 96% attended at least six out of a possible eight sessions. The high attendance was attributed to the acceptance of the classes by the participants. The lowest level of completion was reported by McEwen *et al.* (2010), with only five participants (24%) completing all six sessions. Two studies failed to provide details regarding the completion of the programme/ intervention (Castillo *et al.*, 2010; Lorig *et al.*, 2008).

3.4.6 Meta-analysis

Meta-analysis was conducted on five cognitive outcome measures (self-efficacy, self-reported health, health distress, pain and fatigue) (figures 5, 6, 7, 8 and 9) for the RCTs, all of which used questionnaires developed from the Chronic Disease Self-management Study (Lorig, 1996). All outcomes reported small mean improvements from baseline to six months post intervention. Self-efficacy, health distress and pain all reported statistically significant, but not clinically significant, improvements. Due to heterogeneity between studies and data collection instruments, meta-analysis was not possible for other outcomes. There were not enough studies in any meta-analysis to explore heterogeneity further by meta regression.

Figure 5: Mean difference of self-efficacy up to 6 months follow-up

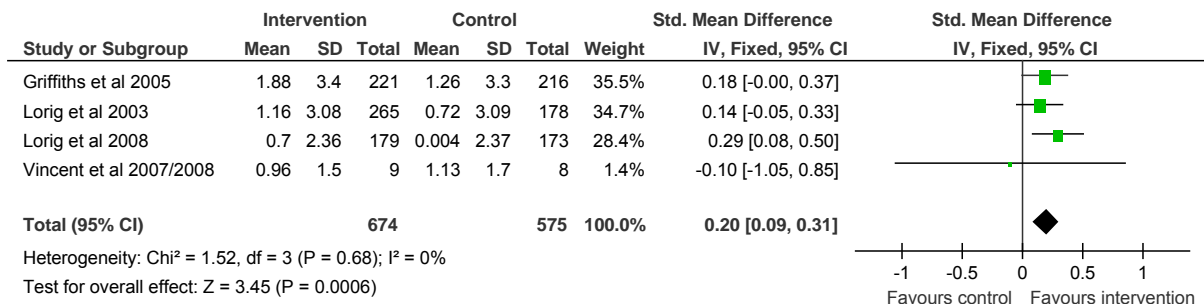


Figure 6: Mean difference of self-reported health up to 6 months follow-up

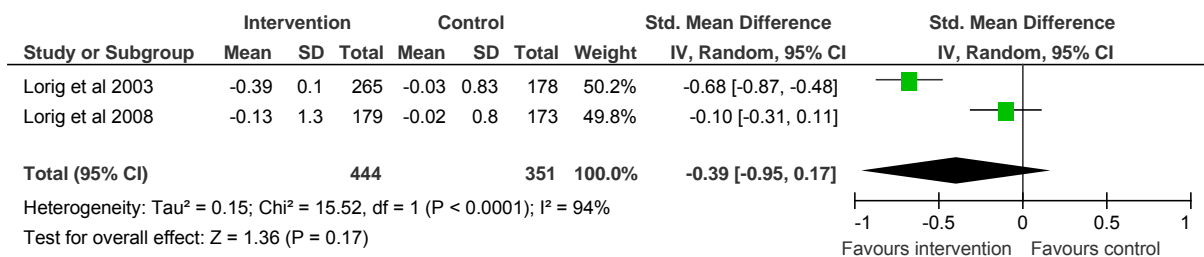


Figure 7: Mean difference of health distress up to 6 months follow-up

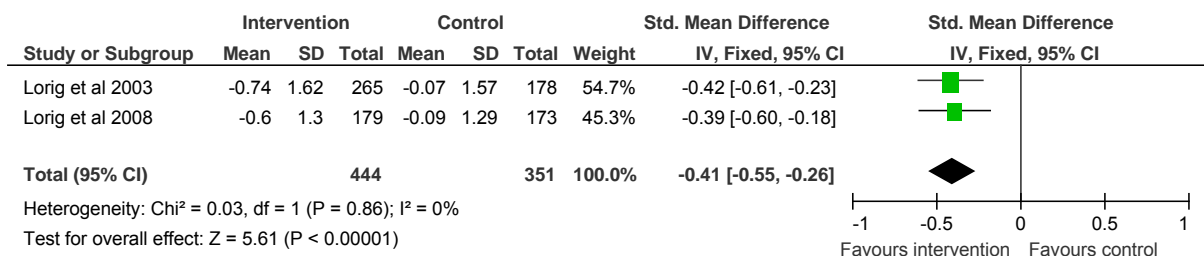


Figure 8: Mean difference of pain up to 6 months follow-up

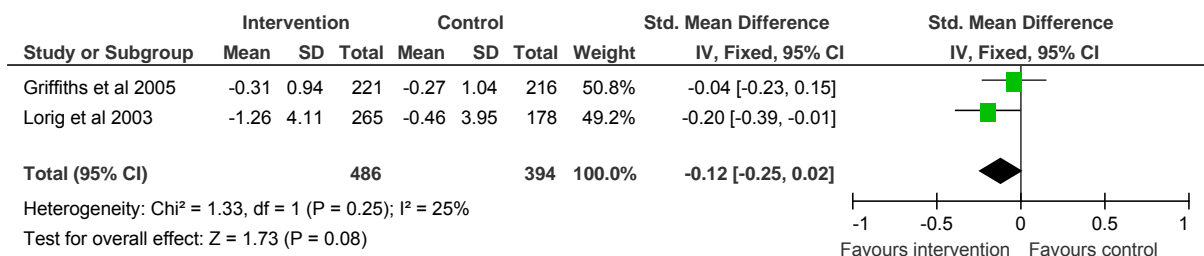
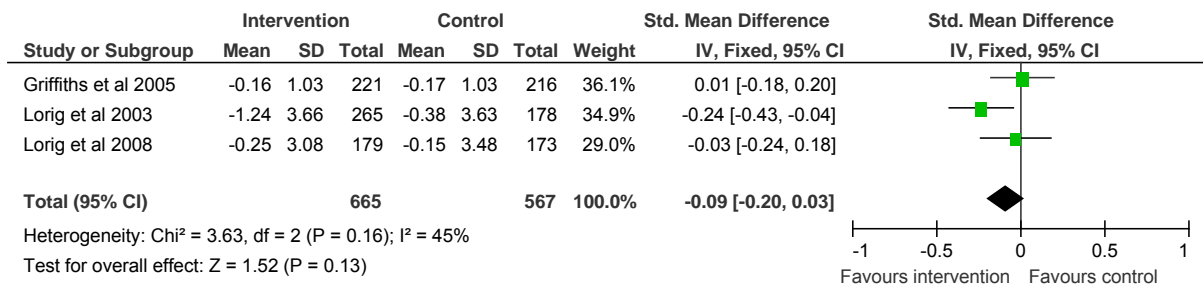


Figure 9: Mean difference of fatigue up to 6 months follow-up



3.5 TAXONOMY OF CULTURAL ADAPTATIONS

A taxonomy of cultural adaptations is presented in Table 9. The purpose of the taxonomy is to describe and evaluate cultural adaptations which can be tailored to self-management interventions for minority-ethnic populations. It is often assumed cultural adaptations will encourage individuals to change their behaviour, but this is seldom critiqued. The taxonomy critiques cultural adaptations made to content and methods of delivery, from a social, cultural and behavioural perspective.

Table 9. Taxonomy of culturally adapted modifications used in interventions

Cultural Adaptation	Definition	Cultural significance*	Behavioural Significance*	Social Significance*
Adaptation to content				
1. Delivery in various community languages	Ensuring the intervention is delivered in a language(s) spoken by the majority of participants encouraged to attend intervention	Clear communication Participants likely to ask questions	Peer identification/social comparison- having a common language may encourage participants to identify with each other	Creating a ‘shared identity’ among participants
2. Cultural adaptation of educational material	Modifying the content of the programme so it covers common beliefs, values and practices of the community	Participants can identify and relate with the material relevant to their lifestyles	Content should be easily implementable in participants current lifestyles Greater understanding of the content with personalised examples Can address beliefs and values that potentially act as barriers/facilitators to behavioural change	May encourage participants from ethnic backgrounds to access interventions Greater discussion on social issues influencing participants lifestyle e.g. low income
3. The application of visual aids and demonstrations	Presenting information with the use of images and getting participants interacting with each other and lay personnel e.g. cooking demonstrations	Intended to make a clear take home message i.e. that certain foods/ practices are detrimental to one’s health	The lay person shows participants how to correctly perform healthier behaviours	Appears to make content easily understandable for participants (as majority are likely to have low literacy levels)

Cultural Adaptation	Definition	Cultural significance	Behavioural Significance	Social Significance
4. Understandable terminology	Use of concepts and language that is understandable to participants e.g. sugar in place of diabetes	Makes content easily understandable to participants who have been accustomed to different terms	Provision of information	Culturally relevant terms carry socially defined meanings that may be correct or incorrect e.g. 'sugar' results from eating too much sugar
5. Emotional well-being	The inclusion of extensive material of emotions (cause of illness, throughout illness, management) and a range of activities to relieve stress	As 'stress' is identified as a cause of chronic conditions by many minority ethnic groups, information and support may be welcomed- content does not de-value community folk beliefs	Can help to reduce stress and anxiety	Identifying social issues that cause stress and better ways in managing stress
Adaptation to delivery				
6. Culturally sensitive approach to delivery	Communicating in a manner that incorporates community values e.g. younger members speaking to elders with respect	Participants feel comfortable in new settings	Participants feeling obligated to the lay person and develop greater motivation to make lifestyle changes	Participants feel like valued members of the group

Cultural Adaptation	Definition	Cultural significance	Behavioural significance	Social significance
7. Recruitment of lay personnel	Appointing members of the 'community' who have greater culturally competent knowledge	Greater understanding of the communities at hand, identification with participants	Increased awareness of barriers and facilitators of change and how behavioural changes could be successfully implemented	Greater understanding of the social problems facing particular communities as they are also part of that community
8. Delivery in community locations	Delivering programmes in locations familiar to communities, within the community, whereby health services can be delivered without rejecting cultural/religious beliefs	Locations may carry some cultural/religious significance	Places of worship could provide greater motivation and support for behavioural changes	Community locations are easily accessible to participants who have limited access to transport
9. Religious/cultural acknowledgement	Inclusion of religious or cultural features that accommodate ones values and beliefs e.g. inclusion of prayer/moments of silence	Encourages members to understand religion can promote feelings of greater control and dismiss fatalistic beliefs	Using practices and techniques that are currently used and can be identified as behavioural practices	Group members may be perceived to be from the same community but may not necessarily hold the same beliefs

Cultural Adaption	Definition	Cultural significance	Behavioural Significance	Social Significance
10. Provision of rewards	Providing incentives for community members to attend and complete the intervention e.g. healthy snacks, exercise tapes, certificate of completion	Encouragement to attend as many may feel reluctant to access services	Praise or material rewards that may possibly be linked achievement	Participants may lack formal qualifications and completion may signify a qualification
11. Provision of healthy cultural foods	Providing healthy snacks or foods throughout the programme that participants can readily eat	Gives participants the opportunity to see and try alternative healthier options that they could purchase themselves	Provides instruction to participants about which foods to buy and which meals to eat	Inclusion of foods that are easily available in particular communities and identified as being healthy e.g. bitter gourd
12. Cultural brand	Changing the name or logo of the intervention so that it represents the community values, beliefs and practices in question	Participants can relate to the programme and identify with the key objectives of the programme	Personalising the programme to participants- may also seem as if the programme has some form of higher approval	Participants may feel less initial apprehension if they are aware of the brand and what it entails
13. Inviting family and friends	Encouraging participants to bring members of their family or friends to the programme	Health care decisions are often shared decisions so it may be beneficial for family/friends to be present	Moral support and encouragement to continue with lifestyle changes/ someone to make changes with	Greater understanding of the practices within families

***Definition of Categories**

Cultural Significance: the importance of acknowledging values, practices and beliefs established within minority ethnic communities

Behavioural Significance: how adaptations to the programme are likely to encourage specific behavioural changes with greater ease and overcoming barriers individuals may potentially experience

Social Significance: how adaptations take into account wider issues that influence an individual's ability to manage their conditions appropriately e.g. low income, unemployment, access to welfare

According to Castro *et al.* (2004), effective cultural adaptations need to go beyond surface structure (changing the ethnicity or appearance of role models) to deep structure, addressing the core values, beliefs and norms of the cultural group (Castro *et al.*, 2004). The majority of the studies showed greater consumption of healthier foods, an increase in the amount of exercise taken, and an increase in self-efficacy post-intervention. Providing information on healthier culturally-specific foods is likely to be better than instructing individuals to consume foods that are not part of their regular cultural diet.

The cultural adaptations made to programme delivery, such as using community languages, providing transportation and choosing community based/ religious locations were associated with high attendance rates across studies. However, cultural adaptations in the intervention did not seem to result in high participation from men, as there was a preponderance of women across all the studies. The cultural adaptations made within lay-led interventions are designed particularly for first-generation migrants. It is unlikely that the same cultural adaptations, such as delivering the intervention in minority languages or the use of visual aids, would be necessary for second-generation participants who may have a greater level of acculturation and are much more likely to have completed formal education.

Cultural adaptations that went beyond didactic content, such as visual aids, demonstrations and audio material influenced cognitive outcome measures, particularly self-efficacy.

Providing information in this way is likely to encourage participants, many of whom have low literacy skills and/or have had little or no formal education, to develop and implement the skills necessary to self-manage their chronic diseases. I conclude that self-management

interventions designed for minority-ethnic populations need to incorporate both practical activities and visual tools to provide self-management information and skills.

3.6 DISCUSSION

This review finds that interventions with culturally-modified components adapted for minority-ethnic populations can lead to short-term improvements in cognitive and clinical outcomes. There were high attendance rates, which may be partly due to cultural adaptations. However, due to a paucity of long term (post 6 months) follow-up conclusions cannot be drawn regarding whether the benefits are sustained.

This review has similar findings to a review conducted by Foster *et al.* (2007); that lay-led self-management interventions can lead to short-term improvements in participants' self-efficacy, cognitive symptom management and self-rated health, together with frequency of exercise. Foster *et al.* (2007) stated the need for longer term outcomes to be collected. In future, studies of self-management interventions need to have a greater emphasis on clinical measures, as the studies included in this review demonstrated poor results in clinical outcomes. The results are unable to determine whether CDSMPs or non-CDSMPs led to greater improvements in cognitive and clinical outcomes.

It has become apparent in the process of conducting this review that there is an urgent need for a universal standard on reporting features of lay-led interventions and aspects of their delivery. The main issue of concern was poor description of the 'lay' individual delivering the intervention. I propose that studies need to ensure a detailed description of the following when reporting on culturally tailored interventions:

- 1) the status of the person delivering the intervention and their cultural heritage/background,
- 2) how they were recruited (organisations and marketing, from the community),
- 3) whether they suffer from chronic diseases,
- 4) their qualifications prior to delivering the intervention,
- 5) the training provided on intervention delivery and by whom (fidelity),
- 6) their specific role and duties/responsibilities with regards to delivering the intervention,
- 7) their previous roles in healthcare settings,
- 8) whether the lay individual delivered the intervention in a community language, and
- 9) any other relevant information that may influence how one may deliver a culturally tailored intervention.

Studies on self-management interventions need to report features about content and delivery that should include:

- 1) where the intervention was delivered and why,
- 2) what behavioural change theory the intervention has been based on (if any),
- 3) the behaviour change techniques used by lay people delivering the intervention (if any),
- 4) a description of the activities and material provided in each workshop and their intended outcomes,
- 5) what support (if any) was provided to individuals outside of workshops,
- 6) whether a manual or protocol was used to deliver the intervention and details on how the manual/protocol can be accessed,
- 7) information on participants who accessed the intervention and those that dropped out (attrition),

- 8) how individuals were referred to the invention, and
- 9) whether any cultural adaptations, either those mentioned in the taxonomy presented in this paper and/or others, were used.

3.6.1 Cultural adaptation

Interventions were culturally adapted in a number of ways. A systematic review by Netto *et al.* (2010) provides a framework to analyse cultural adaptation for interventions designed for minority-ethnic populations. Netto proposes five principles for adapting behavioural interventions for minority-ethnic communities: 1) use of community resources to increase intervention accessibility 2) identifying and addressing barriers to access and participation in interventions 3) developing communication strategies which address language use and differential information requirements 4) identifying and working with cultural or religious values that either motivate or inhibit behavioural change and 5) accommodating degrees of cultural affiliation in the planning and evaluation of targeted evaluations.

All of the studies included in this review used various community related methods to increase accessibility for participants to the intervention, including the use of community leaders or members of the community to encourage participation. The two studies in this review designed for the Bangladeshi community (Choudhury *et al.*, 2009; Griffiths *et al.*, 2005) addressed barriers to access and participation by providing transport from homes to the intervention, gender-specific sessions, and reducing a six session intervention into a one-day workshop to reduce the anticipated high level of drop-outs (Choudhury *et al.*, 2009).

Trials conducted in the US delivered the intervention in a place of worship i.e. churches close to participants' homes. All the studies in this review incorporated lay people that were able to communicate with the population in their native language; in addition, the study conducted with African Americans (Gitlen *et al.*, 2008) used lay terms such as 'sugar' to refer to diabetes. As communities included in this review were likely to have spent fewer years in education in comparison to their White counterparts, many of the interventions modified programme instruments for low literacy levels, with much of the written information given after interventions were delivered.

Only three interventions explicitly addressed religious beliefs with one providing Catholic-based literature (Lujan *et al.*, 2007) while the others included prayers at the beginning of each session (Gitlen *et al.*, 2008; Tomioka *et al.*, 2011). However, interventions that included culturally relevant information on diet, exercise and relaxation also made attempts to address cultural values that may inhibit or motivate behavioural change. For example, Vincent *et al.* (2007; 2009) included content on Mexican American risks, home remedies and family issues while McEwen *et al.* (2010) emphasised the need to be sympathetic to cultural values when delivering interventions to Mexican Americans.

3.6.2 Strengths and limitations

This review was undertaken following recommended methods (Higgins and Green, 2011). Searching was systematic. To reduce the potential for confounding, findings were divided into those from RCTs and other designs. This is the first review of its kind that provides a taxonomy of cultural adaptations which can be used for chronic disease self-management interventions for minority-ethnic populations living in high income countries. In addition, the

meticulous reporting criteria for self-management interventions presented in this review have not previously been reported by other scholars.

This review has a number of limitations. The intended objective was to ascertain the effectiveness of the lay-led interventions. However, the majority of the trials actually reported efficacy, in that they only analysed outcomes of participants who attended follow-up, or those who attended most of the intervention sessions (Lujan *et al.*, 2007). Four of the trials reported effectiveness, using intention-to-treat analyses (Castillo *et al.*, 2010; Griffiths *et al.*, 2005; Lorig *et al.*, 2003; Sixta and Oswald, 2008). This has implications for the interpretation of the findings. The modest effects reported are likely to be further diluted when the smaller effects in people who drop-out from interventions are taken into account.

The application of Abraham and Michie's (2008) behavioural change framework to the interventions in this review was done with great difficulty, because the description of the techniques used to achieve behavioural change was insufficiently detailed. It was often difficult to identify who had conducted group sessions when interventions were delivered by multidisciplinary teams consisting of medical professionals and non-health professionals. A final issue was determining the level of group education delivered by lay people as opposed to other components of an intervention, such as individual support, telephone support and counselling in some studies.

Eight out of twelve studies included in this review were conducted on two communities residing in the US (Hispanic/Latino and Mexican American), therefore, it is unclear whether results can relate to other minority-ethnic populations and especially those that reside outside

the US. The thirteen studies included in this review show self-management interventions were predominantly accessed by women. As papers were poor at reporting details relating to lay people delivering interventions, it remains difficult to conclude whether women's high attendance rates can be linked to the employment of women to deliver interventions, or if there are other reasons. This highlights a need for additional research into lay-led, group-based, self-management interventions, and how they could address the health needs of men suffering from DM and CVD. Further research should concentrate on who should deliver self-management interventions (gender, ethnicity, age), what content should be included and/or omitted, and the appropriate location for an intervention to be delivered.

The studies varied in their measurement intervals with the majority only reporting post intervention results, while others provided results up to 18 months (Lorig *et al.*, 2003). The potential for a high risk of bias was greater in the before-and after- interventions in comparison to randomised controlled trials, particularly in relation to allocation concealment and the blinding of outcome assessors. Other sources of bias were the failure to provide adequate details on the reasons participants gave for withdrawing from the intervention, a considerable risk of publication bias, and searches were conducted in English only (language bias).

3.7 SUMMARY

Lay-led, group-based, self-management interventions are likely to result in an improvement in cognitive factors, but not clinical factors, which may be a result of the nature and methods of delivery of the intervention. The majority of the studies in this review demonstrated high completion and attendance rates in comparison to interventions that are delivered for non-

specific minority populations (Kennedy *et al.*, 2007); however, there remained a preponderance of female participants. Lay people recruited from the target communities to lead these groups can interpret health information and behavioural recommendations in ways that are culturally appropriate, and be better placed to recognise barriers to change. A notable absence was any reporting of smoking cessation as an outcome of interventions, because smoking remains prevalent in a number of minority populations included in this review.

Approaches to cultural adaptation of the interventions largely focused on delivering content in a minority-ethnic language, lay people maintaining cultural customs in the sessions, modifying content with regards to dietary traditions and preferences, and including appropriate educational materials for low literacy populations. The use of goal-setting and creating an intention to change were the most common behavioural change techniques used in the interventions, following Bandura's (1977; 1986) theory of self-efficacy. In the following chapter I present and describe the methods used in my research along with sampling techniques and measures taken to preserve anonymity. In addition, as the research is largely qualitative I provide a reflexive account of the research process detailing my initial thoughts post data collection and how I attempted to establish a relationship with research participants.

CHAPTER 4

4.0 METHODOLOGY AND METHODS

4.1 INTRODUCTION

In this chapter I provide a reflexive account of the methodology and methods selected for my research. I provide a description of the research paradigms that were considered in relation to answering research questions. I continue to describe the process of recruiting participants from minority-ethnic groups that have been traditionally interpreted as ‘hard to reach’ i.e. individuals from the South Asian population, in the UK. I explain the design and selection of data collection methods with the inclusion of codes to highlight the analytical processes that led to the development of themes. I conclude the chapter by discussing the efforts made to ensure findings were credible.

4.2 STRUCTURE AND DESIGN OF RESEARCH

An overview of the structure of the research is presented in Table 10. Table 10 provides details of the aims, research questions, the nature and number of participants included, and the methods used to collect data. The research is constructed into two phases a) a theory-based evaluation (Phase 1) and b) an exploration of health beliefs towards chronic disease and self-management in an at risk population (Phase 2).

Table 10. Overview of the structure of research

Phase	Aim	Research Questions	Population	Methods	N
Phase 1: Theory-based evaluation	To conduct a theory-based evaluation of a lay-led group-based chronic disease self-management intervention	What are the attitudes of lay people delivering self-management interventions to disadvantaged and ethnically diverse communities?	Lay educators delivering the CDE programme	Semi-structured interviews with lay educators delivering the CDE programme	6
		How do self-management interventions affect self-reported participant health status?	Participants that attended the CDE programme from June 2009 to June 2010	Self-reported patient questionnaires relating to participant health status pre and post intervention	1166
		How is the CDE self-management intervention implemented, with regards to content and delivery, for an ethnically diverse community in Birmingham?	All instances when the CDE programme was observed	Observation of the CDE programme	14
		How do individuals living with chronic conditions interpret self-management and services designed to support self-management?	Participants who completed the CDE programme (attended 3 out of 4 sessions)	Semi-structured interviews with participants who completed the CDE programme	20

Phase	Aim	Research Questions	Population	Methods	N
Phase 2: Exploration of health beliefs with regards to chronic disease and self-management in the Sikh community	To develop a greater understanding of chronic disease and self-management with a population that is at risk of developing chronic conditions	<p>What are community member's attitudes and experiences of chronic disease and self-management support?</p> <p>What relationships are important for the mobilisation of support with regards to the management of chronic disease?</p> <p>What are the barriers and facilitators to preventing and/or managing chronic disease?</p>	Individuals across three generations of the Sikh community	Semi-structured interviews with individuals across three generations of the Sikh community	17

4.2.1 Phase 1: A theory-based evaluation

4.2.1.1 Aim and research questions

The aim of Phase 1 was to evaluate an existing model of service provision with regards to chronic disease and self-management for a disadvantaged multi-ethnic population. Prior to commencing my doctoral research, members of the research team had agreed with Health Exchange, the community interest company delivering the CDE programme, to evaluate the intervention. However, details of the evaluation protocol remained undecided and I was given the opportunity to develop and answer research questions I felt were suitable, according to existing research and literature.

As discussed in the background chapter, CDSMPs delivered nationally and internationally, have been theoretically underpinned by psychological behavioural change theories.

Psychological behavioural change theories are based on a belief that an individual's intention towards certain action is based on rational choice and personal goals (Michie *et al.*, 2005). In contrast to this psychological interpretation, sociologists, such as Rogers *et al.* (2009) feel interventions need to concentrate on the social context in which self-management occurs. Bury (1982), another sociologist, emphasises the context in which the meanings of illness are negotiated, with particular importance given to the family.

Hence, as a social scientist conducting applied health services research, my research questions were formulated to understand chronic disease and self-management from a sociological standpoint, as well as recognising the contribution of psychological theories of behavioural change. My research questions specifically focused on the attitudes of lay people delivering

CDSMPs, how CDSMPs are delivered to disadvantaged ethnically diverse communities, and how individuals living with chronic diseases interpret self-management services.

4.2.1.2 Why a theory-based evaluation?

A theory-based evaluation involves identifying the key service components and expected programme outcomes, and working with programmes to make explicit the underlying assumptions about how these service components will lead to desired outcomes (Chen and Rossi, 1983; Weiss, 1998; Bickman, 1987; White, 2005). The advantage of a theory-based evaluation is the focus on the processes that form interventions and the delivery of the programme (Fitz-Gibbon and Morris, 1996). White (2009:274) outlines six key principles of a theory-based evaluation:

1. Map out the causal chain (programme theory)
2. Understand context
3. Anticipate heterogeneity
4. Rigorous evaluation of impact using a credible counterfactual i.e. deviant cases
5. Rigorous factual analysis
6. Use mixed methods

According to White (2005) the application of a well-designed theory-based evaluation addresses questions of why-or why not- an intervention had an intended impact, not just whether it did. My intention to conduct a theory-based evaluation was also influenced by the aims of CLAHRC; to evaluate interventions prospectively with information fed back to service managers that will influence the development of services in the future. As a result, my

intention when deciding to evaluate the CDE programme was not to measure the clinical effectiveness of the programme but to gather a greater understanding of how the programme operates and produces certain outcomes.

There have been other forms of evaluations conducted on recent health interventions, most notably by Greenhalgh (2009) who used realist evaluations (Pawson and Tilley, 1997) to evaluate health services in London. Realist evaluations are grounded in realism, a school of thought that believes social worlds are real and have real effects (Putnam, 1976). However, Greenhalgh (2009) cited great difficulty applying a realist approach to her work, particularly identifying mechanisms, where there was often a number of ‘mechanisms’ that led to a single outcome.

To increase the credibility of the design of my theory-based evaluation I spoke to a number of people involved in the CDE programme; individuals who were part of the design of the programme (Dr Felix Burden, Clinical Director of Commissioning at HoBPCT and Mary Rutledge [MR], Deadly Trio Manager at HoBPCT). A brief, but constructive meeting with the clinical director of commissioning informed me that the CDE programme was based on other generic group-based health education programmes, where it was important to encourage medical adherence and the benefits of diet and exercise for self-management. Therefore, I felt it was imperative that my theory-based evaluation, and presentation of findings, was contextually located with past and existing CDSMPs with regards to theory, design and implementation. This would mean findings from my study would be translatable to other studies of chronic disease self-management programmes.

4.2.2 Phase 2: Exploration of health beliefs in relation to chronic disease and self-management in an at risk population

4.2.2.1 Aim and research questions

The aim of phase 2 was to develop a greater theoretical understanding, with regards to chronic disease and self-management, in an ‘at risk’ community. Findings from the theory-based evaluation showed the experience of attending the CDE programme and living with chronic diseases was very different for individuals from South Asian communities (which are discussed in detail in the following chapters) compared to other ethnic groups. As described in the background chapter, the South Asian population in the UK have heterogeneous beliefs and practices with regards to lifestyle (with notable differences between Sikh, Muslim and Hindu communities) and have a higher risk of developing chronic diseases compared to White Europeans (Gill *et al.*, 2007). Furthermore, findings from the systematic review (Chapter 3) identified inconclusive results in relation to the effectiveness of CDSMPs that have been culturally adapted for minority-ethnic populations.

In an attempt to build from the theory-based evaluation and literature, my research questions were designed to understand chronic disease and self-management in a specific at risk population, exploring the importance of relationships in relation to the mobilisation of support, and identification of barriers and facilitators to self-management.

4.2.2.2. Why explore health beliefs with the Sikh community?

I decided to specifically explore health beliefs within the Sikh community for a number of reasons. Firstly, there were some practical considerations. Within health services research significant importance has been placed on the researcher, by some scholars, having a shared

culture and experience with participants to develop a depth of understanding (Archer, 2002) and my background as a person of Sikh faith allowed me to empathise with participants. I acknowledged that research is not conducted in a vacuum and familiarity with cultural norms and values could increase participation from members of the Sikh community (Serrant-Green, 2002). I also questioned the suitability of culturally adapted CDSMPs, as they are made with the health needs of first generation patients in mind, and not second and third generation who have higher levels of acculturation. The Sikh community is an under-researched group in comparison to their South Asian counterparts, with only a few qualitative studies concentrating on the experience of living with cardiovascular conditions (Bedi, 2008; Galdas, 2012). The intention of this research was to prevent confusion between the terms race and ethno-religious origin when explaining health-related behaviour; the former refers to genetic explanations of health while the latter relates to cultural and personal identity (Johnson, 1996). Therefore, I felt it was appropriate to select the Sikh community as my 'at risk' population with the inclusion of families comprised of first, second and third generation participants with at least one member who suffered from diabetes mellitus and/or cardiovascular condition.

4.2.3 Choosing an epistemological position

Willig (2001) proposes research objectives (or in my case research questions) should determine the epistemological position chosen to address a study's aim[s]. Therefore, I will examine the positivist and interpretivist epistemological positions relative to my research questions. Delanty (1997) argues that the essence of positivism is constructing 'objective' realities based on objects, events or phenomena primarily using quantitative methods. The positivist paradigm seeks to measure, analyse, and generalise data based on an objective

reality independent of human observation (Polit *et al.*, 2003). However, the adoption of a positivist position is widely used in research where every attempt is made to withhold personal beliefs to minimise bias. In recent years, there has been an increasing demand for applied health care research that focuses on the lived experience of self-managing chronic diseases (Kennedy *et al.* 2007), something that is based within interpretivist epistemology.

Delanty (1997) provides an outline of the central features of interpretivism: human action is based on the interpretation of meanings; value freedom (research is largely descriptive but can also be critical), humanism (human nature makes interpretation possible), linguistic constructivism (language defines the social world), and inter-subjectivity (the relationship between the researcher and the researched). According to Wainwright and Forbes (2000) the interpretivist position can provide important accounts of how and why people within different social groups rationalise and explain their views on health. The interpretivist position also highlights the role of researcher, and specifically the extent to which the researcher represents the social world of research subjects, where the process of reflexivity becomes increasingly valuable. Interpretivism advocates the use of qualitative methodology, a methodology widely used to gather data on the subjective meanings behind health beliefs and practices, something that cannot be achieved using a positivist approach. As Denzin and Lincoln (2000) argue:

Qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Denzin and Lincoln, 2000: 3).

Furthermore qualitative methods give the possibility of exploring topics of interest in depth whilst giving the opportunity to expand on open ended research questions (Helman, 1991). As a result of the aforementioned points and the nature of my research questions, an interpretivist epistemological position was adopted using a mixed methods approach.

4.2.3.1 Inter-subjectivity- my reflexive journey

Reflexivity is central to qualitative research where interpretations of the world are shaped by personal values and interests (Hammersley and Atkinson, 1995) and the intention to interpret the individuals' social world in the manner he/she intended (Berger and Luckman, 1967). Therefore, I kept a research diary to record personal thoughts during this study. Reflexive notes also play a role in the analysis of qualitative findings (Mauthner and Doucet, 2003); hence, I ensured my research diary was updated after data collection and initial analysis to record my interpretation of data.

A number of personal factors influenced the design and structure of my study. As a sociologist by background my particular interest is in interpreting social action and how it is determined by personal intentions and relationships individuals have with institutions in a wider social context. As a male researcher I thought this may encourage male participants to talk about their chronic diseases, as men may not want to talk to a female researcher about certain aspects of self-managing their illness. My own ethno-religious status, a person of Sikh faith, partly influenced my decision to research the Sikh community, as I had familiarity with the culture, health beliefs and practices, along with the ability to speak Punjabi. Finally, being born and raised in Birmingham I felt I shared a common background with all my research

participants with regards to having an understanding of the places they lived and subsequently attempting to understand the social issues they faced.

4.2.4 Justification for a mixed methods approach

I selected methods that were most suitable to answer my research questions (Johnson, Onwuegbuzie and Turner, 2007; Morgan, 2007). As the nature of my research questions focused on the context and meaning of human lives and experiences, I needed to use data collection methods that provided detailed information about settings and contexts whilst emphasising the voice of the participant.

Given the research focuses on the experience of living with chronic illnesses and an evaluation of a self-management programme, qualitative methods were most suitable to gain an insight into CDEs' experiences of delivering services, participants' experiences of living with chronic diseases and understanding attitudes towards chronic disease and self-management. I also felt that members of minority-ethnic and low-income populations may prefer to speak about their experiences, as Greenhalgh *et al.* (2005) propose South Asian and illiterate/poorly educated individuals prefer oral communication rather than written material.

Prior to the evaluation, Health Exchange was collecting quantitative data in relation to participants' health status, pre and post intervention. The quantitative data, which I analysed and interpreted with KJ and NG, has been included in this study to establish whether participants experienced any clinical benefits from attending the CDE programme. A 'connecting' data approach (Creswell and Plano Clark, 2011) was applied to integrate qualitative and quantitative data, thus analysing one dataset (quantitative data) and then using

this information to inform subsequent data collection (qualitative data i.e. interview questions). For instance, data from self-reported questionnaires informed research questions explored in the Sikh community.

4.3 ACCESS AND RECRUITMENT

4.3.1 Phase 1: Entry to the field

My experience of gaining entry to the field was somewhat different than the usual practice researchers cite e.g. using gatekeepers (Hammersley and Atkinson, 2007) or being invited by an organisation. A prior relationship had already been established between NG and KJ, and individuals that contributed to the delivery of the CDE programme. I embarked with a cautious approach with the objective of developing ‘handholds and footholds’ (Benyon, 1983: 39) i.e. establishing initial contact which further contact could be based upon. My first contact with CDEs (participants) was at a team meeting.

The tone and demeanour of my first meeting was one of justification and a willingness to create a non-hierarchical relationship (Goetz and LeCompte, 1984; Goodwin, 2006; Oakley, 1981). After explaining my role and the purpose of the evaluation, CDEs were quick to ask a number of personal questions: which university I had studied and which degree I had obtained (determining academic credentials), my past employment and age at the time (determining professional experience) and where I was from (determining personal background).

Retrospectively the latter question was most important in establishing a relationship. I chose to answer instinctively and replied ‘Birmingham’ which I later realised was the ‘right’ answer, as all but one of the CDEs was from Birmingham. This answer was the ice breaker, as

it led to conversations about growing up in different parts of the city and sharing personal stories. Establishing a relationship based on trust was pivotal, as CDEs were responsible for asking participants who had completed the programme whether they would like to be contacted about taking part in this study.

4.3.2 Phase 1: Sampling

A range of techniques were used to generate samples for data collection. At the time of data collection six CDEs were delivering the programme. A population sample, where all participants that form part of the population, were included in the study. Heterogeneity was ensured as CDEs were: male and female, from a range of ethnic backgrounds (Pakistani, Bangladeshi, Black Caribbean, White British, White and Black Caribbean), bi-lingual and non-bilingual, and a range of ages (25 to 40 years of age).

All self-reported questionnaires that were completed by participants between June 2009 and June 2010 (inclusive [13 months]) were analysed. This time frame was suitable as it would allow enough data to be collected and time for analysis in respect to other forms of data collection.

A purposive sampling method was used with regards to observing the CDE programme and participants that completed the intervention (Denzin and Lincoln, 1994). According to Patton (1990) the advantage of using purposeful sampling is the generation of information rich cases that can be studied in depth. In particular maximum variation sampling, a method of generating a heterogeneous sample of participants based on common experiences was used (Patton, 1990). As the aim of the theory-based evaluation was to understand processes in

relation to outcomes, maximum variation sampling provides the opportunity to understand a single phenomenon from a range of different perspectives (Coyne, 1997).

4.3.3 Phase 2: Entry to the field

An initial attempt to recruit members of the Sikh community was made by displaying posters advertising the study in GP surgeries, Sikh temples and community organisations. Posters were displayed in areas of Birmingham that, according to official statistics (ONS, 2011), have a high number of Sikh residents i.e. Handsworth and Handsworth Wood. GP surgeries, places of worship and community organisations expressed a level of scepticism with regards to the number of people who would be interested in taking part. Members of the community would probably know little about how to get involved in academic health research. In six months I was unable to recruit any participants and decided to use gatekeepers instead.

My parents, who have lived within Birmingham and the Black Country for over forty years and built a large social network within the Sikh community, became gatekeepers (Sixsmith *et al.*, 2003) contacting friends and former work colleagues to ask whether they were willing to be part of the study. A number of first generation participants were interested in meeting me to discuss the study and the opportunity to put across their experiences of living with chronic diseases. Informal meetings helped to break ‘us and them’ (Harding, 1987) barriers; a method to familiarise each other, provide information about the study (Appendix 3) and make arrangements for data collection.

4.3.4 Phase 2: Sampling

A purposive sampling method was used to generate a sample with the Sikh community (Denzin and Lincoln, 1994). As the purpose of exploring health beliefs was to develop a greater understanding of chronic disease and self-management, maximum variation sampling provided the opportunity to understand chronic disease and self-management from a number of different people. Generating a diverse sample was important because, as discussed in the background chapter, living with chronic conditions is interpreted to be an individualistic experience. Heterogeneity was ensured as Sikh participants were: first generation migrants (born in the subcontinent), second generation descendants (born in the UK and/or attended compulsory education in the UK from the age of five) and third generation descendants (born in the UK and at least one parent is second generation descendant); at least one family member suffered from diabetes and/or a cardiovascular condition; both male and female; and a range of ages (18 to 77 years of age).

Other sampling techniques were considered. A convenience sample i.e. selecting the most accessible participants was considered (Patton, 1990). However, this technique was deemed inappropriate because it may have led to a homogenous sample e.g. a sample that is more likely to include individuals that are managing their condition well or a greater number of English speaking participants. Therefore, this method carried a higher risk of producing a biased sample and possibly producing poor quality data (Marshall, 1996).

4.4 DATA COLLECTION

4.4.1 Phase 1: Data collection

4.4.1.1 Semi-structured interviews

I conducted semi-structured interviews with Chronic Disease Educators. Semi-structured interviews allow data to be cross compared, as participants are asked similar questions; where the conceptualisation of what participants mean by their responses is made easier (Bryman, 2004; Green and Thorogood, 2004; Legard *et al.*, 2003).

I used an interview guide (Appendix 4) for semi structured interviews, based on a review of the literature on lay people delivering chronic disease self-management interventions and discussions with supervisors (NG and KJ). The interview guide, albeit thematically designed, incorporated both detailed questions and general themes (Kvale, 1996). Questions were open ended, intended to be easy to understand and without academic or medical terminology.

Once interviews began it became apparent that CDEs used interviews as an opportunity to ‘let off steam’ about their role, where my relationship was more akin to participant and confidante (Funk and Stajduhar, 2009):

I don’t know, I don’t know if I’m allowed to say this... (CDE, Interview)

I interpreted the relationship I had built with CDEs as a sign of comfort and rapport I had achieved with participants. I continued to talk with CDEs after interviews, not for data collection but being empathetic to the concerns CDEs had:

Continued to talk after the interview, at considerable length, as during the interview the CDE was quite emotional at times [information on management] (Reflexive notes, post interview)

4.4.1.2 Semi- structured interviews: using a narrative based approach

The nature of inquiry with participants who had completed the CDE programme was exploratory; where I needed a data collection method that allowed participants to develop personal accounts while still collecting specific information about attending the CDE programme. I decided to use semi-structured interviews but with a narrative based approach. According to Onega and Landa (1996), ‘a narrative is the semiotic representation of a series of events meaningfully connected in a temporal and causal way’(pg. 3). The objective of using a narrative based approach was encouraging participants to give descriptive accounts of events that occurred prior, during and after attending the CDE programme in relation to self-management. I again used an interview guide for semi-structured interviews with participants that completed the CDE programme (Appendix 4). All interviews were audio-taped.

4.4.1.3 Observation

To develop an understanding of how the CDE programme worked I used observation as the method to interpret educational delivery and relationships between participants and CDEs, and participants with other participants. The strength of observation as a method is the opportunity for the researcher to witness the actions of individuals firsthand, producing detailed descriptions and explanations, and acknowledging what people say and practice (Mason, 1996). Using Gold’s (1958) typology of participant observer roles as a framework for understanding my role in observing the CDE programme, I took the role of observer as

participant (the researcher has minimal contact in the research setting) to limit the potential of a Hawthorne effect (Roethlisberger and Dickson, 1939). For example, I would greet participants as they entered the room for a workshop but not have any interaction while the programme was being delivered. To make data collection applicable to research questions I recorded observational data using a thematically designed research instrument (Appendix 5) categorised into programme delivery and participant interaction, based on literature and discussions with commissioners and academic supervisors.

I questioned whether it was possible to understand social phenomenon with limited interaction and shared experience with research participants. For example, would it be possible to understand the experience of attending the CDE programme, from a participant's point of view, when I do not suffer from chronic conditions? The skills of the researcher are often an area of concern when using observation as a method (Patton, 1990) i.e. the skill of knowing what to record and what not to record. To overcome such issues, I included a section titled 'additional information' on the research instrument so any information that I felt was relevant but did not fit into pre-defined categories could still be recorded.

The following excerpts, provided from my research diary, were recorded after observing sessions of the CDE programme. It demonstrates the lack of apprehension participants attending the programme had with my presence:

Participant 2 did acknowledge me and made eye contact when talking about her feelings about going to Pakistan, I nodded and smiled back. However, on the whole

other participants acted ‘naturally’ - talked freely and performed tasks as informed by the CDE (Observation, Session 1, Lozells)

During observations, I also ensured that I continued to maintain a relationship with CDEs, often arriving before the course was delivered and left well after it had finished. Other than speaking about how the programme was delivered, it also gave CDEs the opportunity to speak about day-to-day issues:

Spoke to the CDE at length after the participants had left [25 mins]. Just talking about how the session was delivered in a larger group, how [CDE] has to cover other CDE sessions that are away on sick- increased workload (Reflexive notes, post observation)

4.4.1.4 Self-assessment patient questionnaires

Patients that attended the CDE programme (from June 2009 to June 2010 inclusive [13 months]) were asked to complete self-assessment questionnaires at pre intervention, post intervention (week 4 of intervention) and 3 month follow-up (Appendix 6). The questionnaires were designed by Health Exchange with guidance from NG and KJ. The questionnaire covered adherence to medication and physical, emotional and social changes in overall health using Dartmouth COOP Functional Assessment Charts (Dartmouth/COOP Project, 1995). The SF-12 and SF-36 for measuring health related quality of life was not used because previous studies (Jacobson and McNutt, 1998) have described the difficulty of using such tools with ethnically heterogeneous, socio-economically disadvantaged populations. The software package SPSS (version 17.0) was used to quantify data and report mean differences in outcome measures from baseline to 3 month follow-up.

Data on participant demographics, pre and post intervention health status and clinical outcomes was intended to show who was accessing the CDE programme and whether participants showed any improvement from attending the programme in the short term. Questionnaires included visual scales so participants with limited literacy skills would find them easier to complete.

4.4.2 Phase 2: Data collection

4.4.2.1 Semi-structured interviews: using a narrative based approach

Akin to semi-structured interviews with participants that completed the CDE programme, I used a narrative based approach, along with an interview guide (Appendix 4), to collect data from members of the Sikh community. The narrative based approach was particularly suitable for first generation individuals who adopted a ‘sharing stories’ style (Oakley, 1981) within interviews, providing a response and expecting that I also contributed with personal accounts. This ‘sharing stories’ style did lead to greater rapport; participants required little or no encouragement to build on their responses and felt comfortable directing their own accounts. The drawback of the ‘sharing stories’ style, was participants assumed that I understood the context of their narratives. This led to occasions when I needed to ask participants to be explicit in what they meant, an issue reported in other qualitative studies where the researcher and participant share the same ethnicity (Ochieng, 2010).

Participants were reminded that only the research team would have access to their personal information and all comments would remain unidentifiable. Questions regarding confidentiality were much more prominent with members of the Sikh community. Previous studies (Malik, 2000) have mentioned South Asian individuals place considerable importance

on information not being disclosed to third parties, due to issues of honour and shame.

Confirmation of anonymity was an indication from participants that it was safe to proceed with the interview.

4.4.2.2 Interviews with first generation individuals from Sikh community

First generation individuals from South Asian communities are individuals born in the subcontinent and, in their majority, only speak their native languages. Prior to commencing interviews, non-English speaking participants either had information sheets verbally read out to them in Punjabi and provided with an information sheet written in Punjabi (Appendix 7). A number of older south Asian participants (N=3) were unable to sign consent forms with their name, but did so with an 'X' due to illiteracy. Rather than omitting participants from the study, I followed practices outlined on the course *Introduction to Good Clinical Practice* (Birmingham and Black Country CLRN), and made a written note on the consent form stating all questions on the consent form were verbally explained.

Qualitative interviews carried out in languages other than English create different realities based on the nature of talk which is culturally embedded (Temple and Edwards, 2002).

Within interpretive research it is important to view the world from the participant's perspective and acknowledge the language they use to describe it. As certain Punjabi words are not translatable into English, it was imperative that I could understand the social context of individuals experiences through a common language. Hence, priority within interviews was to ensure participants understood the overall meaning of words and questions being asked rather than maintaining a correct linguistic structure.

The way I presented myself also influenced the level of rapport and trust built with first generation participants; not as an academic researcher but as a fellow member of the community. I decided to adopt this approach because I perceived first generation participants would be reluctant to speak to someone who they did not relate with. I took the role of being a ‘family member’ (not biologically related but connected by a common culture and ancestry), addressing participants in a culturally appropriate manner and ensuring participants felt welcomed. There were some boundaries regarding the nature of talk, as certain topics remained ‘off the table’ e.g. sexual intimacy in partner relationships.

Throughout the interviews identity and the role of cultural values was prominent when participants wished to discuss certain issues i.e. caste (Bhopal, 2010). My caste identity (*Jatt* [agricultural background]) became an essential prerequisite in understanding the context behind participant narratives. I remained aware that Sikhism rejects the existence of caste; therefore, I never explicitly asked participants their caste status unless the topic of caste was mentioned within the interview. I shared the same caste status with 15 participants in this study, and I perceived families saw me as ‘one of them’ (Lofland and Lofland, 1995):

We don’t think about ourselves, I mean **our** people, we are always thinking of others... (Interview, First Generation, Sikh community)

Sharing the same caste identity with some participants made it much easier not only to talk about caste but how their practices differed from other caste groups.

4.5 THE RESEARCH SETTING

Elwood and Martin (2000) extensively discuss the importance of location with regards to data collection. I made a number of considerations with regards to location; a) practical considerations such as choosing a location that would be known to participants and easy to travel to and b) locations that would limit the possibility of developing a hierarchical relationship between participants and myself.

4.5.1 The research setting: CDE programme and individuals delivering intervention

With regards to interviewing CDEs, I questioned the appropriateness of conducting interviews in participants' place of employment, as Morton-Williams (1985) argues participants may feel uncomfortable and unable to speak freely in places where they could be overheard. All interviews with CDEs (N=6) took place in their place of employment, in a meeting room that was both convenient and removed from their everyday work space. I also felt conducting interviews in CDEs place of employment would allow CDEs to see me as less of an expert and reduce the likelihood that I may adopt a dominant position within interviews. The CDE programme was delivered in GP surgeries across HoBPCT. Rooms for observation were determined by the space GP surgeries had available, where the research team had no influence.

4.5.2 The research setting: Individuals that completed the CDE programme and the Sikh community

Participants that completed the CDE programme or were from the Sikh community were given the opportunity to be interviewed within their homes, a meeting room at the University of Birmingham, the Central Library (Birmingham) or any other location that they felt was

suitable and convenient. Oberhauser (1997) explains that interviews in participants' homes have the potential of disrupting power hierarchies between researcher and participant. I felt participants' homes were appropriate because it is the location where the majority of self-management occurs; diet, medication adherence, and emotional well-being, to name a few areas. The degree of familiarity and comfort participants have within their homes would be difficult to replicate in other locations. There remained practical considerations, as some participants may not like a researcher, someone they hardly knew, in their homes. As a result, providing a selection of locations was a facilitator to encourage participants to take part in this study.

4.6 ETHICAL APPROVAL AND GOOD PRACTICE

I, along with the research team, obtained ethical approval for this study from a number of different research bodies (Appendix 8-10):

- University of Birmingham Research and Ethics Committee (also covers the Department of Health Research Governance Framework for Health and Social Care), University of Birmingham Ethics Reference: ERN_10-1051
- South Birmingham Research Ethics Committee, Research Ethics Committee (REC) reference number: 10/H1207/71
- NHS permission from the Research and Development department of Heart of Birmingham Teaching Primary Care Trust (HoBPCT), Research and Development Reference: 1425

I undertook research training (Introduction to Good Clinical Practice) as recommended by research governance (Appendix 11). All data was kept on a password protected computer, while paper documents were kept in locked filing cabinet. Participants were informed that interviews would be audio-taped. Interviews were transcribed verbatim. The names of participants were removed from all paper documents and assigned an identification number to preserve anonymity.

Following guidelines detailed by the Research and Development department of HoBPCT, I held quarterly meetings/communication (face to face meetings or email exchange) with the local collaborator, MR (Deadly Trio Manager) at HoBPCT throughout data collection and analysis. The purpose of meetings/communication was to provide updates with regards to conduct of the study. I had monthly meetings with NG and KJ from October 2009 to August 2012 to discuss the conduct of the research and interpretation of findings. Bi-annual meetings were held with TM and PG to discuss the progress of the study. Quarterly steering group meetings were held with the CLAHRC Theme 6 steering group to gain feedback from members of the team external to the evaluation. A member of the HoBPCT commissioning team (MR) was present at the majority of steering group meetings. A report of the CDE evaluation, prepared jointly by the research team (MS, NG, KJ, TM, and PG) was fed back to commissioners at HoBPCT (January 2012) and Health Exchange (February 2012).

4.7 DATA ANALYSIS

4.7.1 Computer assisted qualitative data analysis software (CAQDAS)

I decided to use computer assisted qualitative data analysis software (CAQDAS) to assist my data analysis. I chose to use NVivo 8 on the basis of practical issues; the software package

was relatively easy to use and I had previously used NVivo in my undergraduate degree. The use of CAQDAS can increase rigour and also provide transparency in coding during analysis (Green and Thorogood, 2004: 191).

Transcripts were imported into NVivo, and memo links were made between transcripts and a coding journal to record my interpretation of the data. Barry (1998) and Seidel and Kelle (1995) state that the use of CAQDAS can distance researchers from their data and place greater importance on the frequency of coding. However, it has also been argued that the use of CAQDAS shows how the researcher has immersed himself/herself with the data (Charmaz, 2001). Within this study, I used NVivo to document the coding of data, where, as the researcher, I remained in control of decisions regarding coding and categorising data.

4.7.2 Thematic content analysis

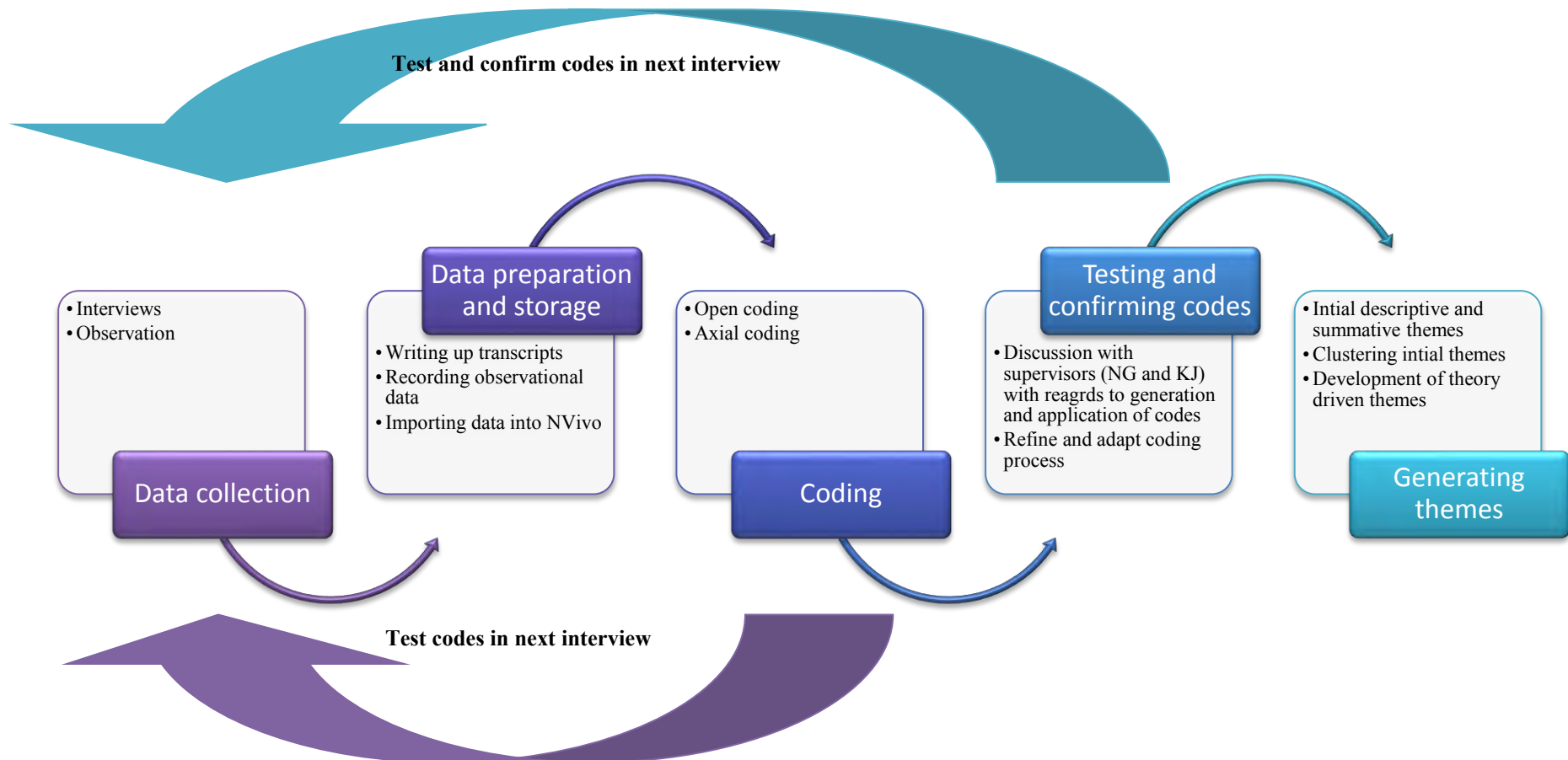
A thematic content analysis was used to interpret findings. Thematic content analysis involves a process of placing data into categories (or codes) to develop analytical categories and eventually theoretical explanations either inductively (generated from the data) or deductively (at the beginning or during analysis) (Pope, Ziebland and Mays, 2000).

Thematic content analysis was conducted using a constant comparison approach. This involved comparing the accounts of all participants on a similar range of questions in order to develop conceptualisations (Thorne, 2000). The overall aim of data analysis was developing theoretical understanding from raw data which was achieved by applying a number of coding techniques, the development initial themes and then combining initial themes to create a theory-driven integrative theme (Section 4.7.3.3).

4.7.3 Coding

According to Saldana (2009) a code is a word or a short phrase which provides a “summative essence capturing attribute for a portion of language based or visual data” (Saldana, 2009: 3). For Miles and Huberman (1994), codes help to catalogue key concepts while preserving the context in which concepts occur. Coding is an iterative process with the researcher moving between stages, and stages often overlap, where data collection and data analysis occur simultaneously. I used my own process of coding data and developing themes, as illustrated in figure 10.

Figure 10: Coding and development of themes



4.7.3.1 First cycle: open coding

First cycle coding involves reading transcripts [and observational data], recognising important segments and encoding data prior to interpretation (Boyatzis, 1998). For Charmaz (1983), working from a grounded theory perspective, “codes serve to summarize, synthesise, and sort many observations made of the data...” and goes on to conclude that “researchers use codes to pull together and categorise a series of otherwise discrete events, statements, and observations which they identify in the data” (Charmaz, 1983: 112).

Once interviews had been typed verbatim, transcripts were read and re-read. A line-by-line analysis (Strauss and Corbin, 1998) was undertaken. Comments were made in a coding journal which referred to finding other data relating to the topic of reference. Comments also included operational notes, such as actions that could be taken in future interviews/observations. Interview transcripts/data from observational sessions were openly coded one at a time. During first cycle coding I particularly focused on the content, i.e. what was being said by the participant/observed. Once all transcripts/observational data were openly coded for each section of the study, my academic supervisor (NG) with a background in qualitative research (with a number of publications in peer reviewed journals) independently coded some transcripts (or sections of transcripts) and checked the coding of observational data.

I openly coded data into descriptive codes i.e. placing data into codes that summarised the phenomena, with reference to guidelines given by Boyatzis (1998: 31):

1. Giving a code a label or a name

2. A definition of what the theme concerns (i.e. the characteristic of issue constituting the theme)
3. A description of how to know when the theme occurs (i.e. indicators on how to 'flag' the theme)

Table 11 provides examples of open codes developed from interviews with lay educators, participants that attended the CDE programme and members of the Sikh community.

Table 11. Open codes developed from data collection

Interviews with Chronic Disease Educators	
Name (Label)	Programme targets
Definition	Aims and objectives that are expected to be achieved by delivering intervention
Description	Attitudes Chronic Disease Educators have towards the achievement of targets outlined by HoBPCT commissioners (delivering nine courses a week) and/or Health Exchange, and how this affects the delivery of the intervention
Example of data	<i>it almost sort of felt we were going from the focus being on the quality to getting as many patients through as possible, at any cost</i> (CDE, Interview)
Notes	<p>The pressure of the CDE role. What expectations did CDEs have prior to applying and beginning position?</p> <p>Operational note: There appears to be a period when there was not such a priority on meeting targets (or less strenuous targets). What led to this change? Perhaps asking next participant to describe times when the focus was not on meeting targets</p> <p>The need for prioritisation with regards to delivering the programme</p> <p>Quality- what factors/components are understood to fulfil a quality programme</p>

Interviews with participants who attended the CDE programme

Name (label)	Reasons for attending (the CDE programme)
Definition	An intention to attend and complete an intervention designed to support individuals suffering from chronic conditions
Description	Any reasons outlined by participants to attend a group-based intervention that could be personally or socially defined. Also the inclusion of deviant cases i.e. those who did not have a reason for attending
Example of data	<i>I don't know what it was about, so I didn't have a reason for not going. I couldn't say, 'I'm not going because ...' because I knew nothing about it. I need to go, assess the situation for myself and then decide whether or not I want to stay with it or not.</i> (Participant, interview)
Notes	<p>Participant had no prior reason for attending the programme. Attending programme due to lack of information, interest to find more about the programme and what exactly it entails</p> <p>No prior intention to complete intervention- but participant did complete intervention- therefore need to understand what participant enjoyed about the experience (latter questions in interview)</p> <p>Lack of information about programme- is there a need for participants to be more informed- would this encourage or discourage people to attend</p>

Interviews with members of the Sikh community

Name (label)	Family history of illness
Definition	The genetic predisposition of developing chronic conditions
Description	Participants narrating illnesses prevalent in their families. Also participants perceived risk of developing conditions that their parents/grandparents are currently suffering from e.g. diabetes, heart disease
Example of data	<i>Obviously I'm conscious, my dad died and he was diabetic, I'm diabetic now as well so yeah that was diagnosed about 18 months ago, type 2 and all the usual sort of stuff so you're conscious obviously that as you're getting older the usual sort of risk factors in terms of weight, exercise, too much eating and drinking and so on</i> (Participant, Second Generation)
Notes	<p>History of illness</p> <p>Knowing that the cause of father's death was related to diabetes</p> <p>Recognition of risk factors- weight, exercise, excessive eating and drinking- already making behavioural changes</p> <p>Fatalism- not religiously defined but understood in terms of genetic predisposition</p>

4.7.3.2 Second cycle: axial coding

After I openly coded transcripts and observation data I used axial coding to develop initial descriptive and summative themes. According to Saldana (2009) axial coding refers to placing relating codes together that are based on a single phenomenon and making connections. Throughout axial coding I also wrote analytical memos. The purpose of writing analytical memos was to detail the development of categories, to make relationships between codes, applying a theoretical interpretation to findings and linking findings with the literature. Detailed below (Table 12 and Figure 11) are axial codes for interviews conducted with participants that attended the CDE programme and an extract from memo writing from observation.

Table 12. Examples of axial codes from interviews with participants attended the CDE programme

Axial code	Open code(s)
Self-management	<i>Attitude to medication</i> <i>Management of chronic condition</i> <i>Physical restriction on body</i> <i>Dietary management</i> <i>Weight management</i> <i>Exercise</i>
Behavioural change	<i>Motivation to change behaviour</i> <i>Responsibility for behavioural change</i> <i>Target setting</i> <i>Experience of relapse</i> <i>Ethnicity related barriers and facilitators of behavioural change</i> <i>Justification for current behaviour</i> <i>Maintaining individuality and independence</i>

Figure 11: Analytical memo on the delivery and learning styles: CDE programme
(observation)

With reference to Freire there are indications that the programme incorporated dialogue exchanges between the educator and participants, with discussion on themes that have relevance to people's lives (Freire, 1972). There were sporadic instances where participants brought elements of discussing their social situation to the group, primarily in the form of the financial barriers they face purchasing healthier products. Discussions centred on educators expressing that healthier choices are cheaper choices in the long term and that participants would benefit from making the changes stated on the programme.

Participants' social situations are not just shaped by their financial difficulties, but also legislative measures and a perceived lack of information about health services. Many of the participants often spoke at length about the levels of salt or fat in the food products they purchased, the number of fast food restaurants in their area, and how the state was not taking invasive action to help individuals live healthy lifestyles. These conversations occurred amongst participants and not with the lay educator. This is important because a core reason in recruiting lay educators from the 'community' was for their knowledge of the social constraints participants faced and yet, in some cases, they are not engaging in such conversations with participants.

4.7.3.3 Developing themes

Bradley *et al.* (2007) states themes are general propositions that emerge from diverse experiences and provide unifying ideas to social phenomena. Axial coding generated themes by conceptually linking codes together. A key practice I adopted when linking codes and developing themes was writing, re-interpreting findings, and re-writing themes. This included a greater focus on the context of findings and moving beyond what the participant said within interviews. In developing and writing themes, it became easier to write small initial descriptive themes, and then clustering small themes into a greater theory-driven integrative theme. Clustering of themes was based on areas indicating consensus relating to research questions and the inclusion of deviant cases i.e. data which disagrees with areas of consensus. Table 13 illustrates the development of a theme from data collected from members of the Sikh community.

Table 13. Development of a theme with data collected from the Sikh community

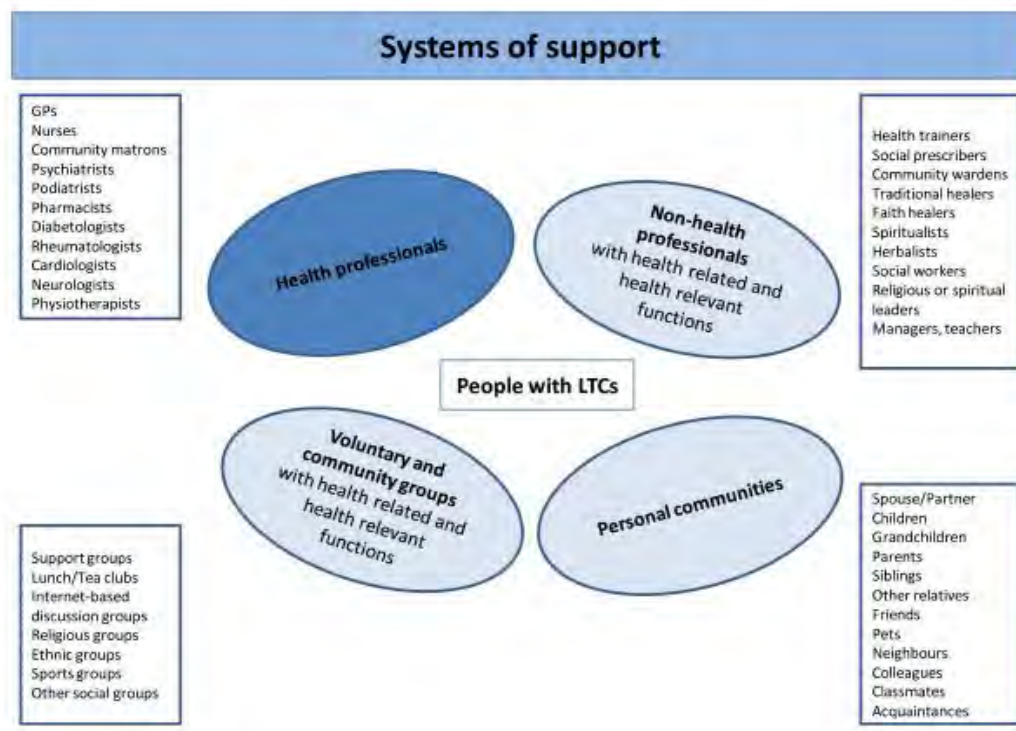
Stage 1. Initial Descriptive theme	Stage 2. Clustering themes	Stage 3. Theory driven integrative theme
Style and quality of consultation Delivery of services Barriers and facilitators to maintaining a healthy lifestyle The use of lay remedies from the subcontinent Emotional well-being and coping mechanisms	Communication- the need for ‘good communicators’ (Lupton 1997). Participants communicating with health professionals (network) with regards to disease management (component of self-managing chronic conditions) Time- using services that are readily accessible Conformity to cultural values and practices- hospitality in the Sikh community Tight-knit families as a source of emotional support Lack of trust in non-health professionals from the subcontinent	The enabling and constraining properties of systems of support

4.7.3.4 Developing themes: systems of support framework

The systems of support framework, developed by Rogers *et al.* (2011), is designed to help understand the mobilisation of resources beyond health professionals and the network of relations that exist with individuals and communities relating to chronic disease management (Rogers *et al.*, 2011: 56). Rogers *et al.* (2011) illustrates the systems of support framework in figure 12 and figure 13. Figure 12 demonstrates four distinct systems of support: health professionals; non-health professionals (with health related and health relevant functions); voluntary and community groups (with health related and health relevant functions); and personal communities. A list of all potential individuals (although not an exhaustive list)

involved in each network is also presented. Figure 13 shows the distribution of responsibility across self-management, chronic illness and social networks.

Figure 12: Systems of support for long term conditions



Rogers *et al. Implment Sci* 2011; 6: 56.

Figure 13: Distribution of responsibility across self-management, chronic illness and social networks



Rogers *et al. Implment Sci* 2011; 6: 56.

After reading transcripts, conducting a line-by-line analysis, coding, writing initial descriptive themes and then clustering themes, I felt members of the Sikh community presented their accounts in relation to the four systems of support outlined by Rogers *et al.* (2011). As a result, the framework was applied to generate integrative themes. I should note that although participants referred to the same broad four categorisations of support, the function, relationships and properties that existed within each network differed (findings are presented in Chapter 8).

4.8 MAINTAINING VALIDITY AND ENSURING QUALITY

Validity, in qualitative research, is the quality of fit between an observation and the basis on which it is made (Kirk and Miller, 1986). One method of evaluating validity in qualitative research is the quality of field work undertaken e.g. the level of rapport between the researcher and participant. This approach has been criticised by Lee and Fielding (2004) who feel that this measure of validity is evaluating the quality of researcher and not the research itself. Habermas (1984) proposes validity is dependent on the researcher acknowledging the background of the research participant and understanding the participant's perspective in the manner they intended. Qualitative research is often criticised for lacking rigour and being subjective (Denzin and Lincoln, 2000). I took a number of additional measures over and above the quality of data collection and analysis, which I will now describe, to increase the validity of my findings.

Triangulation, a process using two or more methods (Denzin, 1988; Morse *et al.*, 2002) was applied in a number of ways. I used data triangulation; using a range of data collection methods (interviews, observation, questionnaires) to enhance the rigour of the study. As stated earlier in the data analysis section, coding and the development of themes was discussed with a number of academic researchers from qualitative methodological backgrounds i.e. member validation (Lincoln and Guba, 1985). I conducted a number of interviews with participants in Punjabi, I transcribed interviews in English and independently checked translated transcriptions with another bi-lingual doctoral researcher (Sandhya Duggal, doctoral researcher, University of Birmingham) to check whether transcription matched audio data and an accurate translation of what participants said was achieved.

Finally, I presented findings in peer support groups and national and international (Appendix 12) conferences to gain constructive feedback with regards to the interpretation of findings.

4.9 SUMMARY

In this chapter I presented my research questions, study design and the methods chosen to collect data. The importance of adopting a reflexive approach to qualitative research has been demonstrated by including extracts from my research diary which made transparent my role throughout the study, from recruiting and sampling potential participants to coding transcripts and developing themes. The importance of conducting interviews with non-bilingual and illiterate participants, and the measures taken to ensure data was collected in sensitive and ethically appropriate manner has also been highlighted. The inclusion of extracts from my data analysis shows the systematic approach taken with data, so findings are credible and not based on my own subjective interpretation. In the following chapter I describe the CDE programme; its origins, content, and aspects of delivery. I will present demographic data about the population accessing the intervention and findings from self-assessment questionnaires in relation to health related quality of life outcomes.

CHAPTER 5

5.0 AN INTRODUCTION TO THE CHRONIC DISEASE EDUCATOR PROGRAMME

5.1 INTRODUCTION

This chapter provides an introduction to the Chronic Disease Educator (CDE) programme and context for the qualitative evaluation. The origins of the programme are described followed by the design, content and delivery of the intervention. Demographic data on patients accessing the programme are presented, with findings from self-assessment patient questionnaires.

5.2 THE CHRONIC DISEASE EDUCATOR PROGRAMME

5.2.1 Origins of the Chronic Disease Educator (CDE) programme

The CDE programme was inspired by an intervention delivered in Turin, Italy called Rethink Organization to iMprove Education and Outcomes (ROMEIO) (Trento *et al.*, 2001; 2002a; 2002b; 2004), with group sessions delivered every three months, facilitated by one or two physicians and an educationist (Trento *et al.*, 2001: 996). The model aimed to verify whether group care could replace individual visits as the main form of outpatient diabetes care, providing a cost-effective and patient orientated approach.

ROMEIO was effective in increasing diabetes knowledge and problem solving ability for patients in the short, medium and long term (baseline to 36 months). The interactive group teaching approach suited adult learners, providing an opportunity to incorporate life experiences to aid understanding and learning (Trento *et al.*, 2002a; 2002b). The results from

the study concluded group care was more effective than traditional didactic methods incorporated in one-to-one visits. Table 14 compares the ROMEO and CDE intervention using the reporting criteria on features about content and delivery presented in Chapter 3. Similar to other group-based interventions, ROMEO (Trento *et al.*, 2002b) was effective in helping patients improve their knowledge of diabetes and increased patients' ability to make informed choices regarding their dietary and lifestyle behaviour. In the medium to long term, patients receiving group care had better metabolic control.

Table 14. Comparison of ROMEO and CDE intervention

Reporting criteria	Intervention	
	ROMEO (2 year follow-up)	CDE Programme
Where was the intervention delivered and why?	Intervention delivered at diabetic clinics (primary care) by one or two physicians and an ‘educationist’	Primary care settings (GP surgeries) and community settings with a single lay educator
What behavioural change theory has intervention been based on (if any)?	No specific behavioural change theory was used	No specific behavioural change theory was used
What behaviour change techniques were used by people delivering the intervention (if any)?	1, 2, 4, 10, 19	1, 2, 4, 6, 8, 10, 19, 22, 24
A description of the activities and material provided in each workshop and their intended outcomes?	<p>Material: undesirability of being overweight, meal planning, improving and checking metabolic control, and preventing chronic complication.</p> <p>Activities: Structure of each session was split into 4 parts: 1) welcome and introduction to the subject to be discussed; 2) interactive learning; 3) discussion of some of the patients’ experiences; and 4) conclusions, with directions for follow-up ‘homework’.</p> <p>Intended outcomes: reach desirable body weight, learn to shop for food, choose appropriate quality and quantity of food, increase physical activity, take medication correctly, understand metabolic control tests, recognise symptoms of hypoglycaemia, action against inter-current illnesses, care for feet, and</p>	<p>Material: information on weight management, choosing healthier foods, meal planning, physical exercise, checking and improving metabolic control and preventing complications.</p> <p>Activities: participants taking each other’s blood pressure, BMI calculations, understanding sugar and salt content in foods (Eat-well plate), food maps, guided imagery, ‘freethink’.</p> <p>Intended outcomes: desirable body weight, learn to shop for food, increase physical activity, take medication properly and regularly, recognise early symptoms of condition, regularly attend clinics, improved</p>

	regular screening and attendance at clinics.	symptom control, reduced BMI, improved quality of life and knowledge of condition, reduced level of prescribing, slower disease progression, management of condition, carry out normal roles and activities, and manage emotional impact of illness.
What support (if any) was provided to individuals outside of workshops?	No contact outside of workshops.	No contact outside of workshops.
Was a manual or protocol used to deliver the intervention and are there details on how it can be accessed?	No information given about the potential use of a manual or protocol.	Manual is available to lay educators, however, not used during intervention. Can be accessed via permission from Health Exchange.
What information is provided on participants who accessed the intervention and those who dropped out?	112 patients, randomised to group care (N=56) and control group (N=56). No information on drop outs. Clinical data provided.	Information is presented in this chapter.
How were individuals referred to the programme?	Patients with T2DM treated with diet alone or hypoglycaemic agents, who had attended their diabetes clinics for at least one year were enrolled in the study.	Patients suffering from diabetes mellitus, coronary heart disease and/or chronic kidney disease were invited to attend the programme. Patients referred to the programme by general practitioners, practice nurses or practice staff. Practices citing a lack of time asked CDEs to contact patients on chronic disease registers directly by phone or postal mail.

Were any cultural adaptations, either those mentioned in the taxonomy and/or others, used?	Application of visual aids and demonstrations, understandable terminology,	Delivery in various languages, cultural adaptation of educational material, application of visual aids and demonstrations, understandable terminology, emotional well-being, culturally sensitive approach to delivery, recruitment of lay personnel, delivery in community locations, and religious/cultural acknowledgement.
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*Abraham and Michie (2008) Taxonomy of behaviour change techniques:

1. Provide general information on behaviour-health link; 2. Provide information on consequences; 3. Provide information about others' approval; 4. Prompt intention formation; 5. Prompt barrier identification; 6. Provide general encouragement; 7. Set graded tasks; 8. Provide instruction; 9. Model/Demonstrate the behaviour; 10. Prompt specific goal setting; 11. Prompt review of behavioural goals; 12. Prompt self-monitoring of behaviour; 13. Provide feedback on performance; 14. Provide contingent rewards; 15. Teach to use prompts/cues; 16. Agree behavioural contract; 17. Prompt practice; 18. Use of follow-up prompts; 19. Provide opportunities for social comparison; 20. Plan social support/social change; 21. Prompt identification as role model/position advocate; 22. Prompt self-talk; 23. Relapse prevention; 24. Stress management; 25. Motivational interviewing; 26. Time management

5.2.2 Design, content and delivery of the CDE programme

The CDE programme was first delivered in March 2008 within general practitioner practices and community settings across HoBPCT. The aim of the service was to provide educational sessions to patients suffering from one or more chronic diseases in a group environment. Patients suffering from diabetes mellitus, coronary heart disease and/or chronic kidney disease were invited to attend the programme. The programme was delivered in 90 minutes for four weeks, once a week, by a single lay educator. Participants were often allocated to groups according to language requirements, with English-speaking participants allocated to groups with an English speaking lay educator and non-English-speaking participants (i.e. South Asian individuals) allocated to groups with a bi-lingual lay educator (Punjabi, Urdu, Hindi and Sylheti). When bi-lingual educators are unavailable, an interpreter with necessary language skills is used. To meet the needs of the local population, the CDE programme recruited lay educators from the 'community'. These were defined as people from different ethnic communities, who lived in Birmingham, and had knowledge of local social issues relating to self-management.

Ten lay educators (CDEs) were initially recruited via advertisements in local newspapers and NHS jobs. At the beginning of data collection (January 2010) four out of ten CDEs had left the programme for positions elsewhere in the health sector. CDEs were required to have (a minimum) of one A level, advanced GNVQ (vocational A level), BTEC national or NVQ level 3. CDEs were also asked to undertake a compulsory foundation degree at Matthew Boulton College, Birmingham to supplement training and development.

The content of the programme includes information on weight management, choosing healthier foods, meal planning, physical exercise, checking and improving metabolic control and preventing complications associated with chronic diseases. Participants were primarily referred to the programme by general practitioners, practice nurses or practice staff. GP practices citing a lack of time and resources to make referrals gave CDEs (or CDEs asked for) chronic disease registers. CDEs contacted patients by phone or by post, providing an outline of the course.

Once participants had completed the programme, it was intended they would have greater knowledge and skills to manage their chronic diseases. The CDE programme needed to be culturally sensitive as the majority of participants using the service came from economically-disadvantaged, minority-ethnic backgrounds with low literacy levels. As well as delivering the programme in community languages a number of other culturally sensitive changes were made to the programme. The following list are the culturally sensitive changes made to the CDE programme using the taxonomy of cultural adaptations, presented in Chapter 3: delivery in various community languages; cultural adaptation of educational material; the application of visual aids and demonstrations; use of understandable terminology; emotional well-being; culturally sensitive approach to delivery; recruitment of lay personnel; delivery in community locations; and religious/cultural acknowledgement.

The programme is delivered by a community interest company called Health Exchange based in Birmingham. Health Exchange was created in July 2006 as part of a partnership development between HoBPCT and Birmingham City Council. In May 2008, the company was re-launched as a social enterprise that was no longer dependent on the PCT or NHS. The

company's aim was to develop services and deliver information that can be accessed by a wide range of communities across Birmingham. Health Exchange was commissioned to deliver the CDE programme by HoBPCT.

5.3 SELF-ASSESSMENT PATIENT QUESTIONNAIRES

5.3.1 Data collection

All participants who attended the CDE intervention were asked to complete a questionnaire in workshop 1 (baseline), and participants who remained in the programme were asked to complete a questionnaire in workshop 4 (end of intervention) and 3 month follow-up (Appendix 6). Data were collected from June 2009 to June 2010 inclusive. The questionnaire was composed of questions relating to individual profile (postcode, age, ethnicity, gender, medical condition and length of diagnosis), medication adherence, and health-related quality of life.

A 4 point scale instrument for medication adherence was used (Kim *et al.*, 2000) (1= None of the time/ 4=All of the time) with questions asking participants whether they forget to take their medication and how they felt, if or when, they missed their medication. Responses related to any period of time throughout the duration of the participant's illness. A total score was generated from the participant's responses to eight questions with low scores indicating better medication adherence.

The Dartmouth COOP Functional Assessment Charts (Jenkinson, 2002; Nelson, 1987) were used to assess health-related quality of life. There were six questions on health-related quality of life: physical ability, feelings, daily activity, social activity, change in health and overall health. For participants who could not read or understand English, questionnaires were completed with CDEs. Participants were also asked to provide weight (kg) and height (m) measurements so a BMI score could be generated (weight (kg)/ height (m²)). A reduction in scores means the participant's health-related quality of life has improved.

5.3.2 Data analysis

Data were analysed at participant level. First sample means, standard deviations, inter-quartile range and percentage proportions were calculated; then, within group changes from baseline (week 1) and end of intervention (week 4) were analysed using paired sample t-tests where appropriate. Due to high levels of missing data at end of intervention (week 4) and the likelihood attendees would have exhibited greater behavioural change than non-attendees, baseline values of missing variables were carried forward and an analysis was undertaken using imputed data. A *P* value of < 0.05 was considered significant. Wilcoxon matched pair signed rank tests were used to measure the effect of change on health-related quality of life scores at baseline and end of intervention as these were not normally distributed.

5.3.3 Results

5.3.3.1 Characteristics of participants

Demographic characteristics from participants who attended the CDE programme are shown in Table 15. During the period of data collection, 1166 participants attended the programme

and completed a baseline questionnaire. Participants had a medium age between 50-59 years, a mean period of 5-6 years since diagnosis (SD 1.9), typically had one chronic illness (75.2% having diabetes mellitus), and 53.3% were female. Participants who attended the programme came (in their majority) from four ethnic groups; 264 (22.6%) White, 233 (20.0%) Indian, 229 (19.6%) Pakistani, and 222 (19.0%) were Black/Black Caribbean. Despite the median age group being 50-59, the sample population consisted of 42% that were less than 60 years old. Only 16.9% stated that they were employed, with the majority retired or unemployed.

Table 15. Characteristics of participants accessing the CDE programme

Variable	N (Valid %)	Birmingham (%)	HoBPCT (%)
Age Group			
less than 40	159 (13.6)	59.4	66.5
40-49	123 (10.6)	12.9	10.8
50-59	272 (23.3)	9.9	7.9
60-69	314 (27.0)	7.8	7.3
70 and over	297 (25.5)	9.8	7.9
Sex			
Male	534 (45.8)	48.4	49.3
Female	622 (53.3)	51.6	50.7
Condition			
		<i>(National Prevalence)</i>	
Diabetes	769 (66.1)	4.0	6.3
Coronary heart disease	62 (5.3)	5.0	2.5
Hypertension	51 (4.4)	12.5	11.1
Chronic kidney disease	11 (0.9)	2.9	2.0
Combination of two conditions	69 (5.9)		
Three or more conditions	21 (1.8)		
Other	180 (15.5)		
Ethnicity			
White	264 (22.6)	66.7	35.8
Black	222 (19.0)	6.7	13.6
Indian	233 (20.0)	6.1	13.4
Pakistani	229 (19.6)	11.2	20.5
Bangladeshi	55 (4.7)	2.3	6.0
Other	163 (14.0)	7.0	10.6
Employment			
Employed	115 (16.9)	46.1	38.4
Unemployed	216 (31.8)	5.7	7.8
Retired	307 (45.2)	12.2	9.9
Other	40 (5.9)	36.0	43.9

Source: Office of National Statistics (2001) (numbers may not add exactly due to rounding of figures)

% may not add up due to some missing data

5.3.3.2 Programme completion rates

Table 16 shows participant completion rates by gender, age group, ethnicity, years living with chronic condition[s], employment status and medical condition. 846 participants (72.6%) completed the programme (attended at least three out of the four weekly sessions), 144 (12.3%) part-completed the programme (attended two out of the four weekly sessions), and 173 (14.8%) did not complete the course (attended one out of the four weekly sessions).

Attendance did not differ greatly with respect to gender, age group, employment status or medical condition. Attendance at the CDE programme differed between participants from the largest five ethnic groups. White British and Black participants had the largest percentage completing the programme whilst the Bangladeshi population had the lowest proportion completing the programme.

Table 16. Course completion rates for the CDE programme

	Number (%) of sessions attended		
	Completed (3/4)	Part complete (2/4)	Did not complete (1/4)
Whole sample	846 (72.6)	144 (12.3)	173 (14.8)
Gender			
Male	389 (72.8)	75 (14)	69 (12.9)
Female	450 (72.3)	67 (10.8)	104 (16.7)
Age group			
Less than 40	116 (73)	22 (13.8)	21 (13.2)
40-49	82 (66.7)	17 (13.8)	23 (18.7)
50-59	197 (72.4)	36 (13.2)	38 (14)
60-69	237 (75.5)	33 (10.5)	44 (14)
70+	214 (72.1)	36 (12.1)	47 (15.8)
Ethnic group			
White	207 (78.4)	22 (8.3)	35 (13.3)
Bangladeshi	32 (58.2)	10 (18.2)	12 (21.8)
Pakistani	154 (67.2)	34 (14.8)	40 (17.5)
Indian	153 (65.7)	36 (15.5)	44 (18.9)
Black	174 (78.4)	23 (10.4)	25 (11.3)
Other	126 (77.3)	19 (11.7)	17 (10.4)
Years since diagnosis			
less than 5 years	151 (72.6)	23 (11.1)	34 (16.3)
5-10 years	126 (68.5)	24 (13)	33 (17.9)
greater than 10 years	119 (75.8)	21 (13.4)	17 (10.8)
Employment status			
Employed	83 (72.2)	14 (12.2)	18 (15.7)
Unemployed	147 (68.1)	41 (19)	28 (13)
Retired	226 (73.6)	34 (11.1)	47 (15.3)
Other	31 (77.5)	5 (12.5)	4 (10)
Medical condition			
Diabetes	572 (74.4)	82 (10.7)	113 (14.7)
CHD	45 (72.6)	7 (11.3)	10 (16.1)
Hypertension	41 (80.4)	7 (13.7)	3 (5.9)
CKD	9 (81.8)	2 (18.2)	0 (0)
Combination of any two	50 (72.5)	7 (10.1)	12 (17.4)

5.3.3.3 Clinical characteristics and health status at baseline

Participants' clinical characteristics and health status scores are presented in Table 17.

Clinical measures were only available for 473 participants. Of participants who completed a baseline questionnaire 51.3% were clinically obese ($\text{BMI} \geq 30 \text{ kg/m}^2$), with a mean BMI of 30.82 (SD 5.98). Participants had an average systolic blood pressure reading of 143.8 mmHg (SD 19.1) and diastolic blood pressure reading 78.3 mmHg (SD 10.8) with 59% having a raised systolic or diastolic reading (>140 or >90 respectively). The mean baseline score for medication adherence was 1.17 (SD 0.58), signifying self-reported medication adherence was quite good. Baseline results for Dartmouth COOP questions highlighted that participants experienced greater restrictions to physical than emotional health. Participants' mean score for overall health was 3.4 (between Good and Fair).

Table 17. Clinical characteristics and health status at baseline

	N (Valid %)	Mean	Standard Deviation
<i>Clinical Variables</i>			
BMI (kg/m ²)	413	30.82	5.98
BMI<25	46 (11.1)		
BMI 25-29	155 (37.5)		
BMI 30+	212 (51.3)		
Systolic BP (mmHg)	473	143.81	19.11
Diastolic BP (mmHg)	473	78.33	10.84
Either SBP≥140 or DBP≥90	279 (59)		
<i>Measurement Scores (Week 1)</i>			
Medication Score	861	1.17	0.58
Physical Fitness Score	988	3.43	1.28
Feelings Score	986	2.48	1.26
Difficultly undertaking activity	996	2.29	1.20
Impact on Social activities	974	1.97	1.19
Participants Health Score	992	2.77	0.90
Participants Overall Health	978	3.40	1.04
Length of time since diagnosis (yr)	549	3.68 (5-6 years)	1.87

BMI: body mass index; DBP: diastolic blood pressure; SBP: systolic blood pressure

5.3.3.4 Change in medication adherence and health-related quality of life post intervention

The results for change in medication adherence and health-related quality of life with participants that completed the CDE programme (completed baseline and end of intervention questionnaires) are presented in Table 18. All six health-related quality of life measures (physical fitness, feelings, difficulty in activity, social activity, health and overall health) significantly improved ($p < 0.05$). There was no change in medication adherence. There was not enough power to detect differences between sub-groups.

When missing data were imputed using baseline values direction of the results did not differ from those for completers only although the effect sizes were smaller. There was no change in medication adherence, but statistically significant improvements for all health-related quality of life measures. Results, using imputed values, are presented in Table 19.

Table 18. Medication Adherence and Dartmouth COOP Questions: mean differences from baseline to end of intervention (completers only)

Outcome	Medication Adherence		Physical Fitness		Feeling		Difficulty in activity	
	N	MD (95% CI)	N	MD (95% CI)	N	MD (95% CI)	N	MD (95% CI)
Overall	550	-0.04 (-0.06, 0.05)	600	-0.33* (0.17, 0.38)	605	-0.34* (0.14, 0.34)	609	-0.39* (0.21, 0.39)
Gender								
Male	205	-0.04 (-0.11, 0.02)	235	0.20* (0.04, 0.37)	240	0.23* (0.09, 0.37)	239	0.21* (0.09, 0.34)
Female	247	0.03 (-0.06, 0.13)	294	0.34* (0.20, 0.49)	295	0.25* (0.11, 0.39)	298	0.37** (0.25, 0.50)
Age								
<40	40	0.03 (-0.16, 0.21)	48	0.21 (-0.17, 0.59)	48	0.04 (-0.32, 0.40)	49	0.06 (-0.25, 0.37)
40-59	154	-0.02 (-0.10, 0.07)	179	0.26* (0.07, 0.45)	186	0.27* (0.11, 0.44)	190	0.34** (0.18, 0.51)
60-74	198	0.01 (-0.2, 0.12)	225	0.31* (0.14, 0.47)	225	0.23* (0.07, 0.38)	228	0.29** (0.15, 0.42)
75+	62	-0.02 (-0.09, 0.06)	80	0.26 (-0.50, 0.53)	78	0.31* (0.12, 0.07)	73	0.41* (0.17, 0.65)
Ethnicity								
White	142	-0.01 (-0.05, 0.02)	156	0.21* (0.02, 0.40)	161	0.26* (0.11, 0.40)	163	0.25* (0.11, 0.39)
Black	93	-0.02 (-0.11, 0.06)	119	0.36* (0.12, 0.60)	118	0.36* (0.11, 0.60)	119	0.47** (0.27, 0.67)
Indian	100	0.00 (-0.23, 0.23)	109	0.30* (0.07, 0.540)	112	0.15 (-0.08, 0.38)	111	0.15 (-0.05, 0.36)
Pakistani	68	0.10 (-0.02, 0.23)	86	0.29* (0.03, 0.55)	84	0.21 (-0.04, 0.46)	85	0.44* (0.19, 0.68)
Bangladeshi	12	0.08 (-0.24, 0.41)	14	-0.21 (-1.21, 0.78)	15	0.47 (-0.19, 1.12)	15	0.20 (-0.67, 1.07)
Others	39	-0.15 (-0.31, 0.01)	48	0.33 (-0.05, 0.71)	47	0.06 (-0.27, 0.04)	47	0.21 (-0.14, 0.57)

* for p<0.05; ** P<0.001

MD= difference in mean scores from baseline to end of intervention for completers

Significance testing used was Wilcoxon Signed rank test

Table 18 (cont)

Outcome	Social Activity		Health		Overall Health	
	N	MD (95% CI)	N	MD (95% CI)	N	MD (95% CI)
Overall	603	-0.27* (0.09, 0.30)	603	-0.50* (0.34, 0.52)	593	-0.36* (0.21, 0.36)
Gender						
Male	235	0.13 (-0.02, 0.28)	235	0.40* (0.27, 0.54)	228	0.22* (0.10, 0.33)
Female	293	0.26* (0.11, 0.41)	299	-0.46** (0.33, 0.58)	291	0.34** (0.23, 0.45)
Age						
<40	47	0.02 (-0.38, 0.42)	48	0.40* (0.06, 0.73)	46	0.00 (-0.31, 0.31)
40-59	181	0.28* (0.08, 0.48)	189	0.49** (0.32, 0.65)	179	0.37** (0.07, 0.24)
60-74	226	0.16 (0.01, 0.31)	223	0.43** (0.30, 0.55)	221	0.25** (0.06, 0.13)
75+	77	0.21 (-0.05, 0.47)	76	0.32* (0.07, 0.56)	74	0.35* (0.16, 0.55)
Ethnicity						
White	163	0.20* (0.04, 0.36)	162	0.30* (0.14, 0.45)	159	0.12 (-0.00, 0.24)
Black	116	0.29* (0.06, 0.53)	124	0.45** (0.26, 0.65)	117	0.57** (0.33, 0.70)
Indian	110	0.16 (-0.08, 0.39)	110	0.37* (0.07, 0.58)	109	0.27* (0.09, 0.44)
Pakistani	79	0.41* (0.08, 0.73)	78	0.62** (0.34, 0.89)	78	0.45** (0.25, 0.65)
Bangladeshi	15	-0.13 (-0.76, 0.49)	14	0.71* (0.30, 1.13)	15	0.07 (-0.64, 0.78)
Others	48	-0.19 (-0.61, 0.23)	48	0.56** (0.32, 0.81)	42	0.10 (-0.17, 0.36)

* for p<0.05; ** P<0.001

MD= difference in mean scores from baseline to end of intervention for completers

Significance testing used was Wilcoxon Signed rank test

Table 19. Medication Adherence and Dartmouth COOP Scores using baseline measure for missing data

	N	Mean	SD	Median	Inter-quartile range (IQR)	P Value
Medication Score						
Baseline	1045	1.09	0.701	1	(1,1)	0.183
End of Intervention	1045	1.10	0.718	1	(1,1)	
Physical Fitness Score						
Baseline	1001	3.39	1.287	3	(3,5)	0.000
End of Intervention	1001	3.24	1.258	3	(3,4)	
Feeling Score						
Baseline	1054	2.44	1.247	2	(1,3)	0.000
End of Intervention	1054	2.32	1.189	2	(1,3)	
Difficulty undertaking activity Score						
Baseline	1065	2.27	1.205	2	(1,3)	0.000
End of Intervention	1065	2.12	1.136	2	(1,3)	
Impact of social activity Score						
Baseline	1046	1.95	1.182	1	(1,3)	0.001
End of Intervention	1046	1.85	1.130	1	(1,3)	
Participants Health Score						
Baseline	1059	2.70	0.944	3	(2,3)	0.000
End of Intervention	1059	2.48	0.949	3	(2,3)	
Participants Overall Health Score						
Baseline	1082	3.46	1.108	3	(3,4)	0.000
End of Intervention	1082	3.32	1.105	3	(3,4)	

5.3.3.5 Outcome analysis- clinical variables

Table 20 shows systolic and diastolic blood pressure and BMI scores in participants who completed a 3 month follow-up questionnaire. Only 30 participants returned for the 3 month follow-up. There was statistically significant improvement in systolic blood pressure, however, BMI increased.

Table 21 shows results for systolic and diastolic blood pressure and BMI scores where baseline observation was carried forward to impute missing data. There was a non-significant reduction in diastolic blood pressure from baseline to three month follow-up (-0.29 mmHg, 95% CI: -0.60 to 0.02, $p=0.06$). Participants demonstrated statistically significant improvements in systolic blood pressure results from baseline to three month follow-up (-0.41 mmHg, 95% CI: -0.79 to -0.04, $p=0.03$) and body mass index (-0.05 kg/m², 95% CI: -0.09 to -0.007, $p=0.022$), however, these improvements were clinically very small.

Table 20. Change in clinical variables from baseline to end of programme (analysis of completers)

	Baseline			End of Programme			Mean difference	95% Confidence Interval		Sig (2 tailed)
	N	Mean	SD	N	Mean	SD		Lower	Upper	
Systolic Blood Pressure	30	142.40	18.10	30	135.87	14.00	-6.53	-0.78	-12.29	0.028
Diastolic Blood Pressure	30	78.40	10.15	30	73.77	10.84	-4.63	-9.51	0.25	0.062
Body Mass Index	27	29.71	5.45	27	29.98	5.40	0.28	0.130	1.329	0.019

Table 21. Change in clinical variables from baseline to end of programme (imputed data using baseline observation carried forward)

	Baseline			End of Programme			Mean difference	95% Confidence Interval		Sig (2 tailed)
	N	Mean	SD	N	Mean	SD		Lower	Upper	
Systolic Blood Pressure	473	143.81	19.11	473	143.40	19.0	-0.41	-0.79	-0.04	0.030
Diastolic Blood Pressure	473	78.33	10.84	473	78.04	10.94	-0.29	-0.60	0.02	0.063
Body Mass Index	416	30.79	5.99	416	30.75	6.00	-0.05	-0.09	-0.007	0.022

5.4 DISCUSSION

5.4.1 Interpretation of results

Participants that completed the CDE programme showed statistically significant improvements in health-related quality of life, systolic blood pressure and BMI at the end of the intervention. Due to substantial missing data and attrition, it remains difficult to know whether improvements were maintained post-intervention. The intervention had no statistically significant effect on patients' medication adherence in a three week period but this may be due to a ceiling effect as medication adherence was reported as high. As the CDE programme is a four-week intervention, it was expected there would be only small improvements in clinical outcome measures, in keeping with studies by Glasgow *et al.* (1989) and Johnson (1992) who report that the relationship between lifestyle changes and clinical variables can often be modest.

Data from programme participation rates show more women were attending the intervention compared to men, but the relative difference was small (7.5%). In comparison to studies included in the systematic review (Chapter 3) and other reviews on lay-led self-management interventions (Foster *et al.*, 2008), there was a higher percentage of men attending the CDE programme and a high percentage of participants completing the programme overall. Results from cognitive and clinical outcome measures are similar to those in studies presented in Chapter 3 and Foster *et al.* (2008): statistically significant improvements in cognitive measures and small improvements in clinical measures. In comparison to other group-based interventions, clinical results from the CDE programme were not as good as the X-PERT programme (Deakin, 2006) (improvements in body weight and BMI) or the DESMOND

programme (Davies *et al.*, 2008), but similar cognitive results as the EPP programme (Kennedy *et al.*, 2007) with regard to improvements in social role limitations.

In relation to cultural adaptations, the CDE programme has implemented a number of modifications presented in Chapter 3, Taxonomy of cultural adaptations; some that were pre-determined i.e. recruitment of lay personnel, while others were included after the programme was commissioned i.e. cultural adaptation of content. Subsequently, the application of cultural adaptations needs to be evaluated to understand how (or how not) they helped participants to take greater control over the management of their chronic conditions. The following chapter aims to address this.

Members from the five largest ethnic minority groups (White British, Black/Black Caribbean, Indian, Pakistani and Bangladeshi) residing in the local area attended the intervention, but participants from South Asian communities were less likely to complete the programme and more likely to drop out compared to White British individuals. Conversely, individuals from Black/Black Caribbean, Pakistani and Indian communities, that completed the intervention, showed some of the greatest mean improvements in health-related quality of life measures, especially change in health and overall health. Thus, there is a need for further research investigating the attitudes of South Asian populations towards lay-led group-based interventions, and health services that can be used for the long term self-management of chronic diseases.

5.4.2 Strengths and limitations

The time between data collection intervals was very short (three weeks), with only a few participants completing three month follow-up questionnaires. Due to a substantial amount of missing data, it is difficult to make conclusions about changes in outcome measures post-intervention. The questionnaires were administered in a non-standardised manner, with lay educators translating questions and/or completing questionnaires with the participant, where responses given by participants could have been biased to please the lay educator. Participants could also 'opt out' from taking BP and BMI measurements on the programme. A possible reason for opting out is participants may have felt their GP has already taken such measurements and taking them again on the programme was unnecessary. There was a large amount of missing data at three month follow-up, which meant imputation was required. Consequently, this means there is degree of uncertainty in relation to results as actual observed values may have been different.

There were a number of strengths with regard to data collection. Data was collected from a large number of people and range of individuals from different ethnic communities representative of the local population. Data were collected using validated measures to determine health-related quality of life. The results fit with findings from the systematic review (Chapter 3) and Foster *et al.* (2008) that lay-led self-management interventions result in small short-term improvements in cognitive outcomes but lack evidence to determine clinical effectiveness.

5.5 SUMMARY

In this chapter a contextual introduction to the CDE programme has been presented. A background to the intervention and its design show how the programme has been culturally adapted to meet the needs of the local population. Demographic data characterises the individuals accessing the programmes in relation to gender, ethnicity and chronic condition. The inclusion of data measuring change in health-related quality of life and clinical outcomes emphasises the short term impact the intervention has on such measures. The following chapter presents findings from interviews with lay educators, discussing their attitudes to delivering self-management interventions to disadvantaged and ethnically diverse communities, and observational data evaluating the implementation of the programme with regard to content and delivery.

CHAPTER 6

6.0 PART A: FINDINGS FROM INTERVIEWS WITH LAY EDUCATORS AND OBSERVATION OF THE CHRONIC DISEASE EDUCATOR PROGRAMME

6.1 INTRODUCTION

In this chapter I present findings from interviews with lay educators and observation of the CDE programme. The aim of this chapter is to understand the beliefs/attitudes of lay educators delivering self-management interventions and how the CDE programme is implemented in relation to delivery and content. A particular emphasis has been placed on evaluating attitudes/phenomena according to different ethnic groups accessing the intervention: White British, Black Caribbean and South Asian populations. It is important that theory-based evaluations acknowledge the context in which data are presented. Therefore, findings have been interpreted with regard to attitudes/phenomena about events within workshops and broader issues with programme implementation outside of workshops. Deviant cases have been included to ensure findings are credible.

6.2 RESEARCH QUESTIONS

In this chapter I address the following two research questions:

What are the attitudes of lay people delivering self-management interventions to disadvantaged and ethnically diverse communities?

How is the Chronic Disease Educator self-management intervention implemented, with regards to content and delivery, for an ethnically diverse community in Birmingham?

6.3 DATA COLLECTION

I interviewed six educators and observed five educators in fourteen different workshops (one CDE was on leave from employment during observations and did not return). The characteristics of lay educators are detailed in Table 22. Observations were conducted in GP practices and health centres across north Birmingham (Great Barr, Aston, Lozells, Nechells, and Handsworth). Four CDEs were given training/seminar rooms to deliver sessions with considerable space for large groups. One educator delivered the course in a GP consultation room. Observations were made with three CDEs delivering the programme in English, one educator using an interpreter (Urdu and Punjabi speaker) and one CDE delivering the programme in a South Asian language (Urdu). I speak Punjabi and Urdu as well as English, so I understood all the dialogue within observed sessions.

Table 22. Characteristics of Chronic Disease Educators

Characteristic	Number of CDEs (N)
Gender	
Male	2
Female	4
Ethnicity	
White British	1
British Asian- Pakistani	2
British Asian- Bangladeshi	1
Black Caribbean	1
Mixed Race- White British and Black Caribbean	1
Age	
Up to 25 years	1
26-35 years	4
36-45 years	1
Language	
Bi-lingual	3
Non-Bi-lingual	3

6.4 FINDINGS

6.4.1 Programme implementation

Receiving a high number of referrals from general practices was perceived to be a prerequisite for successfully delivering the CDE programme. During data collection, lay educators were set commissioner targets of delivering nine complete courses a week. GPs varied in the number of referrals made to the programme, with those referring low numbers making delivery of the programme difficult:

some are very small surgeries so they have to do extra work which takes time to pass on the referrals, with my GPs, about three, four of them are really good they just hand over the referrals and we get decent numbers (CDE, interview).

some of the GP's aren't referring, or they refer like two every now and then, and that can't work because you need at least six people to run a course (CDE, interview).

Subsequently, many lay educators asked practice staff for chronic disease registers so they could contact patients directly, giving them greater control over the referral process. Some general practices were very accommodating while others were reluctant as referring patients to the programme would inevitably lead to an increase in their employees' workload i.e. making contact with potential participants and sending letters of invitation. Lay educators also felt the low number of referrals from certain general practices was a reflection of the lack of knowledge GP's and practice managers had of the CDE programme; what it was and what their patients could expect if they attended. This perceived lack of 'brand' meant lay educators found it difficult to 'sell' the programme to general practices:

We were left to do a lot of the marketing things ourselves, so I wasn't expecting to do that, like go out and publicise what our role was and get things up and running that way (CDE, interview).

According to lay educators, (at the time of interviews) there was an unstable management structure with no-one providing leadership over day-to-day activities. Along with the prioritization of targets, this was felt to be a de-motivating factor:

before we've had stuff on the board where've we got to, how many clients you've seen in a month, initially it was a lot of pressure, there is still a certain amount of pressure, I still actively pursue doing my nine courses, at the moment I think I'm doing about six (CDE, interview).

Attempting to meet commissioner set targets affected the ability to deliver 'quality' workshops and spending greater time with participants, as once a workshop was completed CDEs had to travel elsewhere to deliver workshops to another group. Most often, delivering courses took away time from training and development, which all CDEs wanted to gain and improve. A common area for further development was learning how to deliver the CDE programme to adult learners from various ethnic and economically-disadvantaged backgrounds. Specifically, CDEs wanted to further develop their teaching skills; knowing how to deal with large groups or disruptive individuals rather than learning how to better educate participants:

I think it would be good to have some teaching skills, although I feel as if I'm in a teaching position, which we are, having that little more training and stuff. Sometimes you know, there are different people and they react in different ways to you. They might say something, that might be, might be really awkward so it would be nice to know, good to know, how you deal with it as the teacher (CDE, interview).

6.4.2 Dealing with health beliefs

Lay educators recognised that individuals from different ethnic communities held health beliefs that influenced whether or not participants had the intention of changing their health-related behaviour. Five out of six educators explicitly stated particular health beliefs, relating to people from certain ethnic communities regarding diet and exercise, prevented them from making healthier choices. Dealing with health beliefs was reported by the CDEs to be most prominent with South Asian groups: Indian, Pakistani or Bangladeshi communities. CDEs felt members of these respective communities could be reluctant to make changes. As a result, CDEs expressed frustration because of the constant attempts which had to be made to persuade participants to implement content from the programme:

I usually cater, base the sessions on what Asians would do, the types of cooking they have... cause they'll sit there and say "we don't eat this" and "we don't eat that" (CDE, interview).

Conversely, the majority of the CDEs thought White British and Black Caribbean groups were much more likely to change their health-related behaviour as a result of attending the

programme, as content was perceived to be much more applicable to the cultural lifestyles practiced by these ethnic groups:

Their [White British and Black/Black Caribbean] mentality is slightly different to the Asian culture so you know they don't eat many spices anyway, their lifestyles, their little habits. I find that's its easier for them to make the changes than it is of Asian people because they just have their set plans you know, you make one dish and you have it twice a day, and everybody has the same and you have your chapattis (CDE, interview).

However, not all the CDEs agreed White British and Black Caribbean people would be most likely to implement changes as a result of attending the programme. White British men were identified by one lay educator to have 'negativity', but did not specify whether this was to the certain parts of the programme, or generally towards lay-led group-based health interventions:

I think male groups, especially White males, it takes a lot longer to break down barriers... get rid of a lot of negativity, there's a lot more resistance (CDE, interview).

This resistance, expressed by men, and specifically White British men, is similar to findings from other studies evaluating lay-led programmes concluding men are less likely to attend lay-led programmes compared to women.

The presence of fatalistic attitudes, with regard to religious belief, within South Asian communities is commonly cited in the literature, acting as a potential barrier to behavioural

change. In contrast, CDEs acknowledged participants could either have a positive or negative attitude towards behavioural changes based on religious belief:

in the groups you can tell people that believe in God to people that are non-believers, across the board we get a lot of church goers, a lot of those that go to the temple, they tend to have more of a positive well-being...and yeah some just think if it's God's will then it's God will (CDE, interview).

As a result, CDEs informed participants (who expressed religious beliefs) how their spirituality could be used to better manage their chronic diseases, for example using prayer to cope with everyday stress:

All participants make references to God, Christianity and the Church. All express themselves as god fearing Christians and part of Church groups. CDE explains prayer is a device to combat anxieties throughout their life (CDE, observational notes).

The issue of religion and spirituality was only present in workshops with South Asian and Black Caribbean groups. Women from these communities expressed a strong belief in using religion as a tool for positive emotional well-being. CDEs recognised that members from these respective communities would visit mosques, temples and churches and would provide information about services delivered in locations where individuals could get involved. Nevertheless, it may have been easier to speak about religion and religious beliefs as individuals would often be grouped by language requirements and this often meant they were part of the same religious group.

6.4.3 Cultural receptivity

From the onset, CDEs played a fundamental role in the design of the CDE programme and engaging with external organisations. CDEs were conscious of making the programme suitable for members from diverse ethnic groups. Consequently, this active involvement made CDEs quite attached to the programme, as the CDE programme was considered the product of their contribution and hard work:

This our work, this is our baby, kind of thing, we were the ones that designed it, this is not something the commissioners have designed ... we've had to go out and speak to other organisations and various teams in the NHS to see what there're doing, and design the course around that (CDE, interview).

A number of adaptations were made to content with regard to understanding participants' religious practices and culturally specific diets. Cultural sensitivity, so participants were not offended by content and activities, was also a priority:

if it is an all Asian group where perhaps people don't, no-one's drinks, say if they were all Muslim, really we wouldn't touch on alcohol, it's not relevant at all (CDE, interview).

I mean they all wanna eat healthy but they've all got their individual problems, for example Jamaican's they tend to use a lot of salt on their salt fish and everything, you've got Asian's with the fat and the *ghee* [clarified butter] (CDE, interview).

Cultural adaptations were made, in their majority, to meet the needs of South Asian participants attending the programme. Activities were adapted by incorporating established Asian brands when discussing cooking practices and nutritional value. Female only groups were delivered for Muslim participants on request:

We show them the traffic light system, like types of food, so instead of using English brands I use Asian brands, like East End (CDE, interview).

if it was Muslim women, sometimes they prefer a women only group so you have to be sensitive to that (CDE, interview).

Lay educators interpreted themselves as knowledgeable experts, where knowledge and information they disseminated was thought to be of greater value compared to health beliefs held by participants on the programme. Although it was important to allow participants to discuss their health beliefs, lay educators regularly concluded discussions by distinguishing whether a belief was ‘fact’ (conformed to scientific-based evidence) or ‘myth’ (related to folk beliefs):

they just ask me, “is this true, is this true”, I go this is what’s true and some are myths, so try not to follow the myths just the facts (CDE, interview).

The activities on the CDE programme were culturally adapted to include visual aids for illiterate and/or poorly educated participants to get across the message of healthy eating.

Visual aids were not always applicable to certain ethnic groups, where they would be more useful if they were culturally orientated to meet particular needs for individual communities:

the visual aids aren't culturally relevant, like with the food plate the oils and fats that we've got, even the bits of salt aren't culturally relevant... the oils we purchased from an outside agency, the salt's again have been purchased by an outside agency as well, so it's what they provide (CDE, interview).

Visual aids were perceived to be valuable when educating South Asian members of the group. The CDEs felt that, in general, South Asian people in their groups had lower baseline knowledge of the content provided on the programme compared to people from White British and Black Caribbean communities. For example, CDEs would first explain what the different food groups are before activities using a food mat or food traffic light system were carried out with South Asian participants. The use of visual aids was able to make the 'take home message' of the activities much clearer and easy to understand for members of this group:

The use of the visual aids (images of food portions and the sugar bags- identifying how much sugar is in different types of food) makes a considerable impact on providing a complete picture and makes the content very relevant. PT (1) responds in English, "My God"- PT (5) responds in Punjabi and English combined when she sees a picture of some ice cream, "*bhoort tasty*" [*very tasty*]- CDE picks up image and replies that it is very sugary and unhealthy- PT (1) takes sugar bag- PT (3) in Urdu, "*herani*" [shocked/amazed] (CDE, observational notes).

6.4.4. With or without interpreters?

Throughout interviews, delivering the CDE programme was discussed in relation to the use of interpreters and the differences between bi-lingual and non bi-lingual educators. There was considerable difficulty with using interpreters as often non bi-lingual CDEs would be unsure how accurate a translation was being given:

I don't know exactly what the interpreter's saying or how they're saying it (CDE, interview).

The ability to keep control of the session and ensuring all tasks were completed (by not allowing discussions to continue at length) was imperative for non bi-lingual educators. The use of interpreters could lead to 'chaotic' sessions with multiple simultaneous conversations amongst group participants. CDEs were unsure whether these conversations were about the content they had just covered or something else:

I say it in English then it's translated, it can, I suppose it could become quite chaotic, there's a danger of flicking between two languages (CDE, interview).

However, the same CDE felt the experience of using interpreters can be positive. Interpreters potentially acted as a link between the CDE and members of the community present in the group. Interpreters were members of the very same communities as participants, therefore, the use of interpreters allowed the CDE to build a closer relationship with people from different ethnic communities:

the interpreter that I work [with], they (South Asian community) really value her, yeah, they do, I suppose they're also seen as part of her community as well. Us working alongside together has been, yeah, very positive. I suppose it has broken down perhaps a barrier that may have been between me and the group in a way, if that was ever felt (CDE, interview).

Given the uncertain nature of not knowing what was being translated by interpreters, non bi-lingual CDEs felt it was important to build a relationship with interpreters and set ground rules. The intended outcome of setting ground rules was to avoid miscommunication between the CDE, interpreter and participants:

I think the important thing is when using an interpreter that you sort of clear things from the start, have that understanding of how you're gonna work it, what the procedure is really (CDE, interview).

things that I might be saying in English needs to be re-arranged and described in a certain way, so a bit of knowledge of how you got to say things. Certainly, maybe before sessions, knowledge about the subjects we're gonna be talking about is probably essential (CDE, interview).

Bi-lingual CDEs varied in their attitudes towards delivering the CDE programme in community languages to different ethnic groups. All three bi-lingual educators delivered the CDE programme to South Asian communities. The ability to speak community languages was considered an advantage, resulting in South Asian participants becoming more involved in

sessions by asking questions. CDEs were also able to use their insider knowledge about practices, beliefs or experiences associated with living with chronic diseases:

some groups they do understand you but because they can't speak they can't ask the questions, then if you know the language then they feel more comfortable asking you the question which you can answer in your own language (CDE, interview).

I can empathise with them, obviously I live in the area and you know, I know the community very well, so obviously I can empathise with a lot of the problems and also I've got family who have a lot of the conditions we deal with. I draw on experiences what they tell me (CDE, interview).

Bi-lingual CDEs expressed a number of difficulties delivering the programme to South Asian participants in community languages. Lay educators felt it was difficult to deliver sessions where there was more than one language being spoken; hence, workshops where the CDE would speak both English and a community language. The issue of concern was time, as translating for one group meant others had to wait for the translation to stop and then continue, which was less enjoyable for participants:

I have to be a very strict and say I going do a language only course, cause it's very hard to chop and change, we tried it and it doesn't work...cause it would be a lot easier delivering it to a community language then it is delivering half in a community language then in English and back into a community language, cause people just get frustrated, they get tired (CDE, interview).

The ability to speak community languages meant bi-lingual CDEs were continually given South Asian groups to deliver the programme to. The experience of delivering the programme with South Asian groups repeatedly was challenging, as not only was the CDE expected to deliver the session fluently in a second language but also deal with health beliefs and established cultural practices:

It's quite tiring because working with Asian people is a challenge, because I find it very challenging, because it's a very tough community to work with and especially trying to send out the message that we want, because they're so set in their ways (CDE, interview).

Workshops delivered in Urdu and Punjabi, either through an interpreter or a bi-lingual educator had a 'stop-start' feature. Workshops with an interpreter often involved the educator speaking in English and then the interpreter translating information into Punjabi and, at times, adding more information than what was actually said. The interpreter would often answer patient queries directly as a result of previously working on the programme. CDEs would struggle to control interactions as participants directed their questions to the interpreter rather than the CDE. This often resulted in CDEs explicitly asking what was being said in discussions:

Sorry, so what's being said? (CDE, observational notes).

The use of interpreters and participants with various language requirements created a 'chain of translation', where the information is first delivered by the educator in English, translated

into Punjabi by the interpreter and then further translated into another community language e.g. Bengali, by participants to other members of the group, with information being lost along the chain:

PT 5 states she did not understand the translation delivered to her by the interpreter- firstly in Punjabi, and then does it in Urdu- slightly better. PT 5 speaks Bengali- not spoken by the interpreter which did make her slightly isolated (CDE, observational notes).

Workshops delivered in a single language tended to have less of a ‘stop-start’ feature. This allowed discussions to develop from activities which led to greater participation from the majority of people in a group.

6.4.5 The role of the educator and delivery styles

Throughout sessions CDEs shifted between the roles of an ‘educator’ (providing health-related information through a didactic approach) or a ‘facilitator’ (encouraging participants to direct sessions in areas they feel are relevant and narrate personal experiences). As CDEs were expected to deliver a high number of courses in a single week and considerable content during a four week intervention, five out six educators adopted a didactic educator role, with one educator adopting a predominantly facilitative approach:

I try to keep it relaxed and cater it to what they want it to be, I don’t like it to seem like where lecturing them at all, cause I don’t personally think if you’re telling someone to

do something, or it's like a teaching kind of environment, too formal, I don't think it would work (CDE, interview).

Apart from verbally communicating, CDEs used other techniques to communicate. All CDEs made considerable use of hand movements to convey information or address particular people in a group. Two educators remained seated throughout the sessions, whilst three shifted between sitting with participants and standing in front of the group. Standing gave educators the opportunity to gain the attention of participants and bring discussions to a conclusion. Moving between a standing and sitting position also helped to deal with very vocal participants who spoke over the CDE. Other techniques used to deal with vocal individuals were; CDEs raising their voice to get the attention of the group, asking politely to listen to others as their information may be useful, and one CDE explicitly telling one person to be quiet, which was seen as a last resort.

The number of participants in each session influenced the style of delivery used by lay educators. The greater number of participants in the group made it easier to instigate group discussions either with participants directly or participants amongst themselves. Groups with a small number of participants led to greater probing by lay educators:

if I'm honest the smaller group, one or two, people then it's difficult because some of them maybe don't want to talk, there's only so much probing you can do, but in the bigger group, if one don't talk the other will, so it gets the ball rolling (CDE, interview).

When encouraging facilitation, CDEs developed strategies for increasing participation from group members. One particular technique was to direct questions at members of the group:

Sometimes you have the quiet ones...and try and engage them, and say “what do you think?” (CDE, interview).

Another strategy was to give participants the opportunity to speak to CDEs about personal matters after the session one-to-one and without the presence of other participants. Issues often related to the management of chronic diseases or concerns about health services:

some people don’t want the rest of the group to know, obviously they’ve called me to one side and said [CDE], even something like “I’ve got a problem with the doctor”, something like that, I’ve handed them a PALS information leaflet (CDE, interview).

There were occasions when better informed participants passed on their knowledge to lesser informed participants. Although, once information was passed on by participants they required confirmation from the CDE whether this information was correct or incorrect.

Unsurprisingly, CDEs interpreted themselves as experts; the information they disseminated was based on scientific evidence and consequently valued by group members. CDEs appeared comfortable in an ‘expert-led’ position which allowed them to maintain greater control in sessions. This position allowed CDEs to set parameters of discussion i.e. ensuring participants discussed the content covered and not digressing to personal conversations.

The topic of medication and medication adherence was an area which CDEs felt uncomfortable with. Educators were quick to move away from conversations of this nature

and explained to participants' issues about medication "might be something you want to discuss with your GP" (CDE, observational notes). Interpreters and bi-lingual educators would usually 'work around terminology' with regard to disease-related information for South Asian communities; explaining diastolic and systolic measurements as the top and bottom figure, and the lower the measurement the better (CDE, observational notes). Within these groups, individuals were much more reliant on the educator to provide information and direct discussions, with participants playing the 'pupil' role to the CDE's 'teacher' position.

During the four session programme CDEs were able to build close relationships with participants, regardless of ethnicity, age or gender differences. Female CDEs were seen as 'daughter' like figures that took an active interest in the participants lives through an endearing and caring approach:

Discussion about tension [stress], thoughts and sadness. CDE informing PT 1 to take care of his blood pressure- caring daughter approach (CDE, observational notes).

Five educators felt they made 'bonds' with the participants that would be missed once the programme was completed. However, through observations it remained difficult to understand the type of relationship which developed between CDEs and participants. Participants may have just enjoyed the experience of meeting new people and coming out of isolation, having the opportunity to narrate their personal experiences or acquiring answers to questions which were left unanswered by GPs and other medical professionals.

The close relationship established between CDEs and participants may be a product of both CDEs and participants coming from the ‘same’ communities. CDEs felt part of the communities they were teaching, sharing the same ethnicity, culture and locality, and wanted to ‘give something back’:

I am part of that community that’s where I pretty much, where I live, so yeah I definitely feel a part of it because of my culture, cause of my family history, pretty much everything we discuss in the course, the content of it, is relevant to myself, relevant to my community, relevant to my family, I certainly feel part of the community (CDE, interview).

I’m from the community and I’m working with the community so, I feel as though I’m giving something back (CDE, interview).

This affinity with the ‘community’ is important as it is a key component of recruiting lay workers to deliver health services. Analysis of data showed that in a relatively short space of time CDEs were able to build bonds with members of the community. Through incorporating personal experiences, CDEs were able to better deal with participant dilemmas rather than predominantly relying on validated health information from the NHS.

6.4.6 Using models of behaviour change and behaviour change techniques

The programme was not based on a single behavioural change theory. However, CDEs used a range of behavioural change techniques from a range of behavioural change models either intentionally or unconsciously. The majority of behavioural change techniques used by CDEs

came from two models/theories: social cognitive theory and the health belief model. The most common technique aimed to encourage self-efficacy, i.e. improving an individual's perception that they can successfully perform a behaviour that will have successful outcomes:

CDE stated that going out, socialising, and going to church encourages positive well-being. Participants already confident of undertaking tasks that will improve their emotional well-being (CDE, observational notes).

CDEs also helped participants to identify potential barriers that prevented them from living healthier lifestyles and then cited the perceived benefits; a technique from the health belief model:

The use of persuasion. Outlining the benefits of undertaking certain tasks such as exercise which can improve stress management and (CDE) stating to the participant more exercise will result in a positive outlook; participant nods in agreement (CDE, observational notes).

An essential behavioural change technique in the CDE programme manual is goal setting. Goal setting was primarily performed at the end of the intervention (week 4) rather than setting goals in each session based on the content covered. Furthermore, goal setting was vague and non-personalised; for example, encouraging participants to lose weight but not distinguishing how much weight to lose and over what length of time. Food diaries were inappropriately used on the programme. Rather than identifying potential areas for change in a participant's diet they were seen as a tool that could be used by individuals in isolation.

Therefore, food diaries highlight a potential area where personalised behavioural changes can be made with the help of the CDE:

No recap of the previous week- all participants present in this session were present in the previous session- PT 3,6,8,9,13 bring their food dairies to the session- CDE does have a look at these diaries, however, gives the diaries back to them, “it’s for you guys to use really”. Some appear to think that it was bit of a useless task, maybe wished to gain more feedback from the CDE; advice on where changes could be made, more knowledge and guidance (CDE, observational notes).

The programme lacked any form of testing, either informally during each session or formally at the end of the intervention, to measure how much participants had learnt and implemented since the beginning of the intervention. Nevertheless, one educator individually asked group members (in week 4) what changes they had made since the beginning of the programme:

CDE goes round the table- not asking everyone- on what changes they have made since they began the course- PT 3- “look at labels, more oats, trying to cut down the salt” PT 2-“I’ve learnt a lot, cut down on the chocolate, started telling everyone else” (CDE, observational notes).

6.5 DISCUSSION

6.5.1 Interpretation of findings

Analysis of findings, from interviews and observations with lay educators, shows some general practices were sceptical and unwelcoming towards lay-led programmes being delivered in their surgeries. However, as data were collected when the programme was in its infancy general practices may have changed their opinion of the CDE programme. According to the literature, scepticism held by general practices is not about the content covered but the additional work that may be placed with staff (Frankel *et al.*, 1991). Developing a brand identity may help to change the views of health professionals. For instance, interventions like the Expert Patients Programme (Kennedy *et al.*, 2007), have helped to make chronic disease self-management programmes much more recognisable for health professionals.

Nevertheless, lay educators (and organisations delivering CDSMPs) need to demonstrate how this programme fits with wider health services. A combination of disease-specific and generic health services may be one method of increasing a person's ability to effectively self-manage their chronic disease (Barlow *et al.*, 2002). This could potentially lead to a greater number of referrals being made by general practices, a feature which was considered essential to successfully delivering the CDE programme. Lay educators may benefit from formally being introduced in a team model with health professionals (GPs, practice nurses): lay people, from the local community, playing a valuable role by providing contextual information about a patient's attitudes, behaviour, and environment (Martinez *et al.*, 2011).

The training needs of lay people delivering group-based health education to minority-ethnic disadvantaged populations need to be examined. CDEs identified two main areas for further

training: controlling groups of adult learners without causing offence and how to work with interpreters. In contrast to findings presented by Brown *et al.* (2007), CDEs did not express any need to develop their knowledge on healthy living or chronic diseases as they were comfortable dealing with health beliefs held by members from various ethnic communities. There was a need for ethnically-appropriate tools to be used within the CDE programme. Most of the equipment was externally brought from the United States and subsequently more applicable to western diets. Through observation of the CDE programme it was clear lay people delivering self-management interventions need to be adequately trained (or undertake further training) in techniques which encourage a person to change their behaviour. The techniques that need to be developed are:

- 1) recognising which behaviours to change,
- 2) making explicit the health benefits of making changes,
- 3) setting realistic targets (use of SMART goals or action planning),
- 4) reviewing targets, and
- 5) informing individuals how to deal with potential setbacks.

The definition and application of these techniques have been explained in *Improving Health: Changing Behaviour, NHS Health Trainer Handbook* (Department of Health, 2007). The handbook, designed for health trainers, includes information about many of the skills lay people delivering self-management interventions require. It is difficult to determine whether the CDE programme would have benefited from the application of a behavioural change model, such as social cognitive theory or the health belief model, as lay educators were still able to change a participant's behaviour. There is a lack of strong evidence with regard to the

benefits of using behaviour change theories in health education. A recent review by Taylor *et al.* (2006) found small differences in the effectiveness of various behaviour change theories with regards to changing knowledge, attitudes and/or behaviour for clinical and cognitive health outcomes.

The CDE programme lacked a method of formally or informally testing what participants had learnt during the course and whether they were applying knowledge in their everyday lives. Testing participants at the beginning of the intervention may help lay educators develop a greater understanding of the learning needs of people from different ethnic and socio-economic backgrounds. Previous studies have shown members from minority-ethnic communities are less knowledgeable with regard to health information but show significant improvement after completing self-management interventions (Castillo *et al.*, 2010; McEwen *et al.*, 2010). South Asian participants, particularly, were less knowledgeable in relation to identifying healthier foods, the benefits of exercise and how to manage self-perceived stress compared to their Black Caribbean and White British counterparts. Consequently, by testing participants' knowledge at the beginning of the course the content could be altered to meet the needs of the group.

The group-based approach led to peer-to-peer interactions but these were often discussions about the content rather than exchanging skills and/or learning from each other's experiences. Interventions designed for people living with chronic conditions should encourage participants to talk about their experiences with the aim of learning from each other. Peer-to-peer learning could be achieved with exercises conducted in pairs; for example, diabetic members talking about healthy foods which prevent fluctuations in their blood sugar levels.

6.5.2 Cultural adaptation

6.5.2.1 Adaptation to content

Cultural adaptations to the CDE programmes had both advantages and disadvantages.

Workshops delivered in a single language (either English or community languages) resulted in clearer communication because there were no interruptions for translation and subsequently leaving participants waiting for the workshop to continue. Conversely, group sessions in multiple languages resulted in patients misunderstanding the content, patients feeling isolated in group discussions and content being repeated by the educator. Interpreters can help lay workers build relationships with minority-ethnic groups but caution is needed to ensure they do not take on the role of the educator. Nonetheless, having courses delivered in community languages allows participants to be directly involved in interactions enhancing face-to-face communication and participant-educator rapport which can lead to the development of strong bonds (Scheppers *et al.*, 2006).

Altering the content to include Asian brands and foods made the intervention more personalised for South Asian participants. However, certain South Asian foods and cooking practices may not be applicable to White and/or Black Caribbean people accessing the intervention who have their own methods. Visual aids were effective in promoting healthy messages for those with limited prior knowledge of healthy behaviours.

6.5.2.2 Adaptation to delivery

The predominantly didactic approach adopted by lay educators, due to targets and covering tasks in a short period of time, deterred educators from taking a facilitative style.

Subsequently, participants were not encouraged to narrate personal experiences of living and

managing their chronic diseases. Lay educators recognised the importance of accommodating religious/cultural beliefs as participants expressed both fatalistic (religiously interpreted) and cultural health beliefs. Lay educators should encourage patients (who express faith) to understand that religion can play a positive role in self-management and include prayer or moments of silence for workshops delivered to black and minority-ethnic (BME) groups.

Self-management interventions need to recognise participants bring existing ways of managing their chronic illness and health beliefs that have been legitimised through social, cultural or religious practices (Gately *et al.*, 2007). Participants can only alter these beliefs if knowledge of better self-management is constructed with the lay educator, where they are given the opportunity to narrate their personal experiences without the need to move on to complete other tasks.

6.5.2 Revisiting the literature: Originality of findings in this study

Previous qualitative studies about lay educator's perceptions of delivering CDSMPs have focused solely on their role within workshops or training (Brown *et al.*, 2007; Rhodes *et al.*, 2007). This study has also focused on the role lay educators play outside of workshops and the wider implementation of interventions such as recruiting practices. Consequently, this helped to gather a greater depth of understanding with regards to factors which influence how lay educators deliver CDSMPs to economically-disadvantaged minority-ethnic groups. In addition, findings suggest that lay workers should be embedded in primary care as the majority of courses were delivered in general practices, clinical data could be collected in partnership with GPs and general health information could be provided readily.

Apart from verbal communication lay educators also demonstrated the usefulness of other techniques. This is the first study which comments on the role of non-verbal communication techniques in a CDSMP delivered to an ethnically diverse population in the UK. Lay educators should be trained to effectively use non-verbal techniques such as using standing/seating positions to begin, facilitate and conclude discussions during workshops.

6.5.3 Strengths and limitations

There are a number of limitations from this phase of the study that should be considered when interpreting findings. The number of lay educators interviewed was limited (N=6) as many had left their positions for employment elsewhere. Nevertheless, all lay educators that were delivering the CDE programme (at the time of data collection) were interviewed. The strength of data is the range of groups that were observed; groups delivered in various community languages, male and female, from different ethnic-groups and ages. Furthermore, conducting interviews and observation allowed the possibility to explore a range of topics with regards to content and delivery of self-management interventions. Combining two methods (observation and interviewing) also helped to reinforce findings and subsequent conclusions about the CDE programme.

6.6 SUMMARY

CDEs felt the process of recruiting surgeries, contacting patients and reaching commissioner set targets required considerable time and effort. There was a constant need to distinguish between health beliefs and legitimately correct health information. CDEs felt most comfortable when leading the group, however, there are areas in which CDEs remain uncomfortable; dealing with issues of medication adherence and identifying opportunities to

apply behaviour change techniques. South Asian participants were perceived to benefit the most from the application of cultural adaptations, as the programme met their language requirements and information was contextually relevant to their particular lifestyles. The next chapter presents findings from interviews conducted with participants who completed the CDE programme. The chapter examines how people living with chronic conditions manage their illnesses, how they interpret the experience of attending lay-led self-management interventions, and whether they changed their behaviour as a result of attending the programme.

CHAPTER 7

7.0 PART B: LIVING WITH CHRONIC CONDITIONS: INTERVIEWS WITH PARTICIPANTS WHO COMPLETED THE CHRONIC DISEASE EDUCATOR PROGRAMME

7.1 INTRODUCTION

In this chapter I present findings from interviews with participants who completed the CDE programme. The aim of this chapter is to understand how participants interpret self-management and services designed to support self-management of chronic diseases. The chapter presents themes in relation to two areas of interest: themes concerned with the management of and living with chronic diseases; and themes about the experience of attending the programme such as the group experience, opinions about the educator, programme content and delivery, and what participants learned and/or changed about their behaviour. Akin to the previous chapter, a particular emphasis has been placed on evaluating the experience of living with chronic conditions by ethnicity, gender and age.

7.2 CHARACTERISTICS OF PARTICIPANTS

The characteristics of participants are presented in Table 23.

Table 23. Characteristics of participants who completed the CDE programme and were interviewed

Characteristic	Number of participants (N)
Gender	
Male	11
Female	9
Ethnicity	
White British	7
White Other	1
Asian- Indian	5
Asian- Pakistani	1
Asian- Bangladeshi	2
Black Caribbean	4
Age	
40-49	4
50-59	3
60-69	10
70 or older	3
Years since diagnosis	
Less than 5 years	7
5-10 years	4
10 years or more	9

7.3 RESEARCH QUESTION

The following research question is addressed in this chapter:

How do people living with chronic conditions interpret self-management and services designed to support self-management?

7.4 FINDINGS

7.4.1 Who is a lay educator?

7.4.1.1 Understanding the role of a Chronic Disease Educator

The promotion and development of chronic disease self-management programmes has led to an array of terms being used to describe lay people, such as peer mentors, peer leaders, peer educators, lay health workers, community health workers, community health educators and many more. These terms are often used interchangeably. However, each of these terms contain subtle differences with regards to responsibilities, duties held and why a particular lay person was considered suitable to deliver an intervention to a given population.

Unsurprisingly, participants were unfamiliar with the term ‘Chronic Disease Educator’, the role, or the qualifications a CDE had obtained, participants had no preconceptions about CDEs:

The impression I got with him ... I was a bit apprehensive about him, but when he started talking ... I think if you need to ask him, he was there to ask (CDE-ATT-17, Male, White British, T2D and heart conditions).

But whatever we asked him he tried to explain to us as best as he could, because we don’t know how qualified he was, but we were all asking him questions and he was

trying to answer them as best as he could (CDE-ATT-08, Male, White British, multiple conditions).

7.4.1.2 The relationship between participant and Chronic Disease Educator

This lack of information was not detrimental to the subsequent relationship which developed between participants and CDEs during the programme. The relationship was based on trust and rapport, with CDEs showing empathy and understanding with regard to the concerns of the participant:

I felt that she [CDE] was very empathetic, I found her very understanding and I could talk to her, cause occasionally there were times where you would like to talk to her on a private matter, she was very good there, she listened very carefully and was very helpful to me... I found her very understanding (CDE-ATT- 14, Male, White Other, T2D and Stroke).

The closeness of the relationship was signified by participants referring to CDEs by their first name or as the person delivering the programme. None of the interviewees used the term Chronic Disease Educators or CDEs. The relationship between participants and the CDE was, paradoxically, given value and meaning through comparison with the relationship they had with their GP. The CDE was addressing shortcomings participants identified with their GPs; CDEs were able to spend greater time with participants and explain how a change in their lifestyle could help them better manage their chronic diseases:

He was mostly happy with the fact that on how she[CDE] advised on how to lose the weight, how to minimise your food [consumption] and stuff because he wasn't very aware of it (CDE-ATT-07, Male, Asian Bangladeshi, T2D, via interpreter).

it didn't feel like I was taking to a doctor or a nurse, they felt like part of the family and I felt it was more helpful (CDE-ATT-03, Female, White British, multiple conditions).

However, not all participants were dissatisfied with their GP. The GP was identified as an important health professional, with regard to managing chronic condition[s], ensuring a person's condition and health status was being monitored:

he'll (GP) test your blood, your heart and your feet and all that, he's pretty good, that's the way I find him (CDE-ATT-10, Female, Black Caribbean, T2D).

Those who were happy with the care they received from their GP felt the CDE programme was a supplement to their current care. As the letter of invitation was sent by GP surgeries, participants felt a perceived sense of assurance that the content had been approved by their GP:

You know my doctor send me the letter through the post, so I read it and I started to go over there, I mean this is, the programme is very good (CDE-ATT-15, Male, Indian, T1D and heart conditions).

The close relationship between CDEs and participants could be a product of their recruitment ‘from the community’, as CDEs were thought to have a greater understanding of participants’ experiences based on a shared background. Nonetheless, interviewees’ expressed differing attitudes to having members of their ‘own community’ delivering the CDE programme, as many felt it made little or no difference:

[Interviewer] So, was it of any benefit that [CDE] was from a similar background?

[Respondent] No, whoever’s a good person, like we speak to White people, we speak to Black people, so what’s wrong if everybody is friendly with each other (CDE-ATT-13, Female, Asian Indian, heart conditions).

South Asian respondents, overall, valued CDEs from their community largely because they were able to deliver the course in community languages. Instances where there were ethnic differences (Indian Sikh participant/Pakistani Muslim CDE) made little or no difference, with the exception of one person who felt a ‘bit more comfortable that she [CDE] was Pakistani’ (CDE-ATT-12, Female, Asian Pakistani, T2D):

she was telling everyone in Punjabi, do this, do that, she spoke good Punjabi, sometimes she spoke in English, everything was fine with her (CDE-ATT-11, Female, Asian Indian, T2D and Hypertension).

lovely young fella, you know, because we more or less adopted him (CDE-ATT-05, Male, Black Caribbean, T2D).

The relationship was also influenced by the mode of delivery chosen by CDEs and participants' prior knowledge of self-managing their chronic conditions. The relationship was described either as informal and friendly, or 'teacher-pupil' with a clear focus on learning:

No, no it didn't feel like a classroom at all, no, it was just like you were going in to have a talk with a normal friend in a friendly atmosphere (CDE-ATT-03, Female, White British, T2D).

[CDE] was very good too. I think it was just the sharing, the company and no, I think so. Because if [CDE] was a grumpy person or whatever, I wouldn't go back. He could stay here all by himself. I wouldn't go back (CDE-ATT-04, Female, Black Caribbean, T2D).

She [CDE] was quite sincere and know her stuff, obviously she did her homework, she wouldn't have got the job otherwise I suppose (CDE-ATT-16, Male, Asian Indian, heart conditions).

Members from various ethnic groups experienced different types of relationships with CDEs. White British and Black/Black Caribbean interviewees described the relationship as informal; based on personal conversations, friendliness, and listening. In contrast, South Asian interviewees described a formal relationship based on learning and developing skills that would potentially improve the management of their conditions. South Asian participants appeared content with a 'teacher-pupil' relationship acknowledging that the CDE was better informed and should lead workshops. The 'teacher-pupil' relationship is explored further in the following section: learning styles and delivering the programme.

7.4.2 Learning styles and delivering the programme

7.4.2.1 Determining the value of information

During the programme it was envisaged participants would learn from the CDE and their peers within the group. It was intended the group-based format would encourage peers to share experiences and exchange self-management skills. Yet, participants placed greater value on information given by CDEs, particularly information on healthy foods:

It was very good in that, because he had it on the board and he would say that is that, that is that, and so many calories or so many grams is in that, as simple as it may be ... the other thing which he beat on about is salt, he say don't take so much salt and I say I use LoSalt [branded reduced salt product], him say still don't use it so much because at the end it's still so much, the grams in there (CDE-ATT- 10, Female, Black Caribbean, T2D).

Visual aids were interpreted as valuable resources when promoting 'healthy' messages and used in a variety of ways; providing a pictorial representation of the damage certain foods have upon certain organs e.g. blocked arteries around the heart, and bags of sugar and tubes of oil demonstrating the quantity of each in particular foods. A number of South Asian interviewees commented on the importance of reducing their portions and the types of oils they should use for Asian cooking, with visual aids making information easier to understand and remember:

She was telling us about what things we should be eating, with all her things, in this there was so much sugar, she had these little bottles of sugar ... eat that, do this, do that (CDE-ATT-13, Female, Asian Indian, T2D and heart conditions).

The greater value and meaning given to information provided by CDEs did not prevent participants from questioning the legitimacy of the information. This referred not only to information provided by the CDE but health professionals as well:

I'd go somewhere, like I'd go to the hospital and they'll say eat a lot of fruit and I'd go to the nurse at the doctor's and she'd say don't eat a lot of fruit because it contains a lot of sugar, so we were stuck in the middle there of who to believe (CDE-ATT-08, Male, White British, multiple conditions).

7.4.2.2 Peer-to-peer learning

Group members were much more critical when accepting information from their peers. Peer-to-peer exchanges were constructed on sharing personal narratives; discussing past experiences of living with and managing conditions. Newly diagnosed participants benefited from listening to participants who had lived with their conditions for longer; learning 'what to look out for' (CDE-ATT-05, Male, Black Caribbean, T2D) and building confidence to either begin or continue good self-management:

a lot of the other people they had more ailments I thought than I did, although I had ailments, or else I wouldn't be there and it's good to know what they do to combat the problem they've got (CDE-ATT-16, Male, Asian Indian, heart conditions).

but other people would go into a lot of detail and things like that, and sometimes what there're saying I think that applies to me as well though I don't like to talk about, so that gives me a lot of encouragement especially if they've lost a lot of weight because I think they've got the same problem I've got and they've managed to lose all that weight I can do it, it proves to me I can do it provided I put my mind in gear (CDE-ATT-09, Female, White British, T2D and heart conditions).

Nonetheless, there were participants who felt it was difficult to accept information from peers because they perceived each person's experience of living with and managing their chronic conditions as different. For example, participants living with diabetes spoke of dealing with hypoglycaemic episodes or 'hypos', where each participant described a different way of managing such events:

if you ask another person with diabetes, he will tell you his experience, you could ask a hundred people, if you talk to a hundred people they all give you their advice, of their experience, but sometimes it doesn't work with you, you know (CDE-ATT-15, Male, Asian Indian, T2D).

Because we're all individuals, what suits me, they could not copy me because it may not suit them (CDE-ATT-04, Female, Black Caribbean, T2D).

Interpreting the experience of living with chronic conditions as individualistic may explain why participants placed greater value on information given by the CDE. If the experience of living with a chronic condition is specific to each person then it becomes increasingly difficult

for participants to begin to learn from each other. Although, greater value placed on information given by the CDE could be a result of information being much more generic; healthy foods, information about diseases and better emotional well-being, information which can be given without personalising content. When there were instances of peer-to-peer learning i.e. exchanging and using advice given by group members, better informed participants would inform less knowledgeable members about practices they should not adopt:

They [other members of the group] were talking about the food, they changed their food, like their *atta* [flour], they changed it to wholemeal, then there were other things they said (CDE-ATT-13, Female, Asian Indian, heart condition).

But you know to a lot of degree you learn from other people's mistakes (CDE-ATT-05, Male, Black Caribbean, T2D).

The most important aspect of sharing personal narratives in a group format was the development of an informal environment to discuss emotions. Participants were able to share their emotional experiences of living with chronic conditions and the subsequent development of coping strategies:

[Interviewer] What things did you pick up from the other people in the group?

[Respondent] Mainly the way they were coping with it [diabetes]... there were two, Type A [Type 1] and all the rest of us were Type B [Type 2]. But it was the way they coped, more than the people who'd got diabetic group A [Type 1], the really bad one.

And I found them fascinating because they seemed to be coping with it so well. (CDE-ATT-01, Male, White British, T2D).

There was a lack of facilitation from CDEs when participants shared personal experiences. Greater facilitation by concentrating on positive experiences e.g. appropriately dealing with hypoglycaemic events, rather than negative experiences could potentially result in greater peer-to-peer learning. Furthermore, if the CDE can confirm appropriate self-management practices or highlight inappropriate practices participants may value information provided by their peers more. There was one significant drawback of sharing personal narratives. In large groups (6 or more members) it was difficult for everyone to have an equal amount of time to speak about their illnesses, often competing with other participants and/or content that needed to be covered:

All we heard was about their illnesses and you think to yourself well we've all got illnesses, we all want to speak to [CDE] about them (CDE-ATT-02, Female, White British, heart conditions).

7.4.3 Medical knowledge versus lay knowledge

A key part of living with chronic diseases was attempting to understand the cause of illnesses. Interpretations generally lay within two fields of thought: medical knowledge (understanding causality with scientific evidence) and lay knowledge (understanding causality with reference to folk beliefs common in cultural groups, past experiences of living with chronic diseases and/or accounts from close family/friends). In the following sub-themes, I discuss which

forms of knowledge are used by participants to describe and interpret the cause of their chronic diseases.

7.4.3.1. Medical explanations

During interviews participants were asked to recall and describe (if possible) events that led to their diagnosis. A memorable event was the consultation in which participants were diagnosed; where they were usually informed a family history was a factor that potentially contributed to the onset of their illnesses. If there was no family history the likely cause was understood to be a poor lifestyle:

It's inherited. My father and his side of the family, most of them are diabetic (CDE-ATT-04, Female, Black Caribbean, T2D).

at one time I could have said that cause I was eating a lot of chocolate and 'sweetie' things (CDE-ATT-04, Male, White Other, T2D and Stroke).

Age was also recognised as a factor which contributed to the onset of chronic conditions, where a number of participants felt as they became older they were inevitably more prone to developing certain ailments:

I'm of the opinion of the GP's [and] any other medical bodies, with age the blood pressure increases anyway so I put it down to that (CDE-ATT-16, Male, Asian Indian, heart conditions).

Stress was another factor recognised which contributed to the onset of conditions, but rather than a single cause it was one factor among a number of risk factors. Stress was mentioned by the majority of South Asian and Black Caribbean interviewees and socially contextualised:

it's just that I know it's stress, the way of my busy lifestyle, the way I would not sit down properly (CDE-ATT-12, Female, Asian Pakistani, T2D).

it was very, very emotional at times because it was so stressful and I think anyone who's in a job now is very stressful (CDE-ATT-05, Male, Black Caribbean, T2D).

7.4.3.2 Lay explanations

Lay explanations towards causation were presented through cultural and religious beliefs. Individuals born outside of the UK (first generation participants) from Black Caribbean and South Asian communities believed foods produced in their country of origin were healthier compared to foods available in the UK:

I'm saying is things are cultivated differently and additives, like insecticides and other preservatives and other stuff; I'm not convinced that that's not playing a part in our health (CDE-ATT-04, Female, Black Caribbean, T2D).

You can definitely taste it, it's a lot fresher particularly if you live in villages where the food is more or less a day old, compared to here, it might be three or four day's old (CDE-ATT-16, Male, Asian Indian, heart conditions).

South Asian interviewees often tried to explain their community's greater prevalence of chronic disease through cultural preferences in food which placed them at greater risk. Particular attention was placed on cooking methods, arguing food was often over cooked and subsequently there was a need to replace nutrients with additional supplements:

why do we [South Asians] have sugar [diabetes] when White people never have sugar, have any of them got it, only a few, but our people don't eat good food (CDE-ATT-11, Female, Asian Indian, T2D).

...because I don't [get] enough nourishment from the food, because we [South Asians] over cook the food you know (CDE-ATT-15, Male, Asian Indian, Male, T1D).

These quotes show members of the South Asian community are beginning to question health beliefs surrounding their cultural diet and re-examining established cooking practices. Nevertheless, some health beliefs remain prominent; for instance, the amount of sugar eaten predominantly influences blood glucose levels, as the one Bangladeshi male explains how he manages a hypoglycaemic episode:

Afterwards, about five or ten minutes after, then it gets back to normal, I eat some sugar, so when my sugar is low, I eat some sugar, then I am ok (CDE-ATT-19, Male, Asian Bangladeshi, T2D).

The practice of eating sugar to control blood sugar levels was not only present among South Asian people, but also one White British male describing a similar method. Finally, a commonly held belief was ensuring a strict routine was followed, especially with regards to

medication taken at similar times each day, allowing a person's body to become accustomed to treatment:

It's automatic now, I get up in the morning, I take my tablets, I take them again at two o'clock, that some more at five o'clock, and I take some more when I go to bed at night, but it's just automatic (CDE-ATT-08, Male, White British, multiple conditions).

7.4.4. Incorporating new skills

7.4.4.1 The social considerations of making behavioural changes

Incorporating behavioural changes required participants to re-evaluate their current health and lifestyle, with consideration of their personal intentions and wider social factors. The food industry was identified as playing a significant role in the choices people made about their lifestyle, where participants argued the government should take greater responsibility in controlling the amount of fat, salt and sugar in foods:

Because they're [food manufacturers] the ones that are making these foods ... they're the ones that are putting these ingredients and this sugar into our foods (CDE-ATT-02, Female, White British, heart conditions).

The government is on about we should eat more healthily and that, so why don't they do something about these McDonalds, shut all of them down then. I know everybody to do their own type of these; it's up to us individuals if we go in there (CDE-ATT-17, Male, White British, T2D and heart conditions).

One male interviewee emphasised how important the role of the government was by describing how legislation which led to the smoking ban in public spaces influenced his health behaviour:

if you notice now that a lot of pubs out there are closing and the only reason they are closing is because of the smoking ban, which is a good thing don't get me wrong, but people feel now that if you are going out and you can't sit down and enjoy a drink and a smoke what's the point (CDE-ATT-05, Male, Black Caribbean, T2D).

Another area of concern was the numerous changes in the type of 'branded' medication participants received from their local pharmacy/chemist. One woman felt changes in the type of medication she received was a politically motivated effort to reduce the cost of caring for people living with chronic diseases:

Why are they changing their suppliers so frequently, because if it was the same supplier you wouldn't be able to afford to keep changing the packaging? You wouldn't be able to afford it because it's expensive. So why do they need to change so frequently? How many suppliers have they got? Where are these pills coming from? (CDE-ATT-04, Female, Black Caribbean, T2D).

But a lot of the GPs are very aware of their budget. They will not stretch that extra inch if it means them spending an extra pound. It's more a business than it is a caring

thing. It's them looking after themselves. It's a GP thing. It's all budget (CDE-ATT-04, Female, Black Caribbean, T2D).

Evidently, medication adherence was an important aspect of self-management. Making sure medication was taken meant individuals were less concerned about maintaining lifestyle changes. One female explains how taking glucose lowering agents for her diabetes means she can be less restricted with her diet:

I'd got to keep a watch on my diet because it was diet controlled [diabetes], well with my Metphormin [oral anti-diabetic drug] I can have the odd bit of stuff if I fancy like a bit of chocolate ... at least I'll know if I take my sugar level it's not going to go sky high or it's not too low, where before I'd check it two or three times a day to make sure I hadn't ate anything [that] would cause it to go sky high or anything (CDE-ATT-03, Female, White British, T2D).

However, the recognition of social factors did not devolve participants of personal responsibility, as most felt they played the most important role in managing their condition. In contrast, this woman demonstrates the level personal responsibility and accountability involved with medication adherence:

you have to take them [tablets]... you have to take them, if you don't take them then it's not his [GPs] responsibility, he'll say why didn't you take your tablets, so that's what it is, so the medication that has begun, you have to take it, that's not going to stop (CDE-ATT-11, Male, Asian Indian, T2D).

7.4.4.2 CDE programme: knowledge acquisition and skill development

During interviews participants were explicitly asked what they had learnt from attending the CDE programme. The CDE programme supported individuals by reinforcing public health messages, such as eating at least five fruit and/or vegetables a day:

She [CDE] said if you want to eat grapes have a handful of grapes, a medium banana, two plums, that's your three a day, then two vegetables, that's your five a day, isn't it (CDE-ATT-13, Female, Asian Indian, heart conditions).

Overall, South Asian interviewees reported learning more about healthy lifestyles and management compared to White British and Black Caribbean interviewees, as they felt the CDE programme helped to remind or confirm what they already knew rather than teach them anything new:

It just confirmed what I knew and, on some occasions, helped me think, "Oh right, I understand that a bit better now" (CDE-ATT-01, Male, White British, T2D).

The general information about the diabetes, you know, if you've got a heart problem, a liver problem, they give you all information, they tell you about the food, which is the good food, which is the bad food. All this information which I never had it before, I never had it you know, so alright you go to the doctors but they don't have much time to explain to you, so I think this sort of programme it helped (CDE-ATT-15, Male, Asian Indian, T1D).

All participants spoke of behavioural changes which they had recently made or changes they intended making in the near future. The process of making and maintaining behavioural changes were seen negatively; a restriction on their lifestyle and a sacrifice which meant no longer taking part in enjoyable activities:

I've got to change, I must change my ways of eating and I did. OK, fair enough now and again I think, "is it worth it?" and I'm thinking, "do you want a good quality of life or not?" So if you want a good quality of life, you've got to change and that's what I started to do. I changed (CDE-ATT-17, Male, White British, T2D and heart conditions).

Sometimes when your friends say, "do you want to come out for a drink?" I end up say well no 'cause I can't really have a drink, so it's took most that part of it [social life] (CDE-ATT-03, Female, White British, T2D).

Some changes were made but significantly adapted according to cultural habits. Older members of the South Asian community were especially reluctant to try foods they felt were not part of their cultural diet. These participants preferred to maintain practices that were culturally approved rather than choosing healthier alternatives:

Lamb we do once a week or twice a week (CDE-ATT 12, Female, Asian Pakistani, T2D).

Although, two individuals incorporated diet related changes by replacing South Asian foods with non-Asian alternatives:

I've started to eat wholemeal bread, so instead of having two *roti*'s [chapatti] I'll have four slices of the brown bread, which is more fibre (CDE-ATT-13, Female, Asian Indian, heart conditions).

In the three weeks I didn't eat chapatti either, brown bread, just brown bread (CDE-ATT-18, Male, Asian Indian, heart conditions).

For some, the programme appeared to play a key role in clarifying misunderstandings attendees had of health information and subsequently incorporating new skills. In addition, participants reported how they had introduced information from the programme, namely checking the nutritional values of food products:

with [CDE] he has told you, you know what's in certain food and how much stuff is in it and what its containing, 'cause I used to love grapefruit but I can't touch them because of my cholesterol and it was only through [CDE] that I knew I couldn't touch them (CDE-ATT-03, Female, Female, multiple conditions).

I know you're allowed 2500 calories, there are 119 calories in a packet of crisps...I have Quaver's which only have 87 calories in, I'll have one of them (CDE-ATT-17, Male, White British, multiple conditions).

In general, participants found regular exercise much more difficult to implement and maintain in comparison to dietary changes, often citing a lack of time or other responsibilities e.g. caring for others. Similar to the literature, members of the South Asian community were most likely to cite a lack of exercise, where walking would be most common. In comparison, White British and Black Caribbean individuals were regularly exercising:

He does sometimes walk, but sometimes not every day, probably once or twice, probably three times a week, just to the mosque and back, that's it (CDE-ATT-07, Male, Asian Bangladeshi, T2D, via interpreter).

I walk sometimes five, six miles every morning routinely. I work on allotment, where I'm going off to in a minute (CDE-ATT-04, Female, Black Caribbean, T2D).

I go to this gymnasium three times a week and I do a hour on a treadmill, I do six kilometres (CDE-ATT-20, Male, White British, T2D).

Nevertheless, there were some participants who reported making no behavioural changes since attending the programme. These were people who felt comfortable with their existing methods of self-managing and attended the programme to gain a greater understanding of their current practices:

It just confirmed what I knew and, on some occasions, helped me think, 'Oh right, I understand that a bit better now' (CDE-ATT-01, Male, White British, T2D).

A key feature of making and implementing behavioural changes, in relation to lifestyle, was practicing restraint. For instance, the greater the number of foods removed from a diet was an illustration of the level of restraint shown:

I stopped eating red meat, I didn't eat dairy produce, I didn't eat cheese or eggs, I didn't have butter (CDE-ATT-20, Male, White British, T2D).

Participant accounts also differed with regard to responsibility. Participants who spoke about the range of behavioural changes made remembered fewer 'episodes' when they were unable to manage their condition e.g. hypoglycaemic events. Still, the process of making behavioural changes was often difficult due to personal circumstances. The following male participant describes how his attempt to stop smoking was hindered by family-orientated issues:

Obviously you quit because you know damn well it doesn't do you any good. Yeah, I probably would like to quit. I haven't got the willpower and I've had a...it sounds pathetic, the family have had a really rough time over the last four years or so (CDE-ATT-01, Male, White British, T2D).

7.4.5 Living with chronic conditions

The experience of living with chronic conditions had similarities and differences across participants from my sample. Interviewees often lived with multiple conditions which included: diabetes, CVD, leukaemia, depression, stroke, bi-polar disorder, epilepsy, and breast cancer (remission).

7.4.5.1 Coping with physical impairment and emotional distress

Individuals living with multiple conditions (which did not include a mental illness) placed more attention on the condition that could potentially lead to the greatest deterioration in their physical health. A number of interviewees who lived with diabetes would often fail to mention they also suffered from hypertension:

[Interviewer] So, it's just diabetes that you have?

[Respondent] Yes, yes.

[Interviewer] Any heart conditions?

[Respondent] Just [high] blood pressure (CDE-ATT-15, Male, Asian Indian, T2D and heart condition).

Therefore, participants living with multiple conditions placed greatest importance on conditions which require greater attention on what they are eating (low in sugar, fat and/or salt), maintaining a stable body weight and medication adherence. Accounts with participants living with mental illnesses as well as chronic conditions were characterised by experiences of emotional instability and inability to carry out everyday tasks. Dealing with emotional instability was imperative for women as it led to significant uncertainty over self-managing:

I really do get some days where I'm so depressed and I just don't want to do anything. I feel like I want to give up and when I get them days it's horrible, it really is, you just don't know what you are going to do (CDE-ATT-03, Female, White British, multiple conditions).

One Asian Indian female, who suffered from bi-polar disorder, felt there was a social stigma attached to having a mental illness which was culturally interpreted as ‘madness’:

leading an Asian life, it’s very hard when you have a an illness yourself because when you have a mental illness yourself they say that you’re *baa-gal* [mad], that doesn’t mean to say that you’re not human (CDE-ATT-13, Female, Asian Indian, T2D and bi-polar disorder).

Female patients were much more vocal and expressive about the way in which their mental illness impacted upon their daily lives. They felt that their mental illness required separate but equal amount of attention and responsibility in comparison to physical restrictions associated with chronic diseases.

Living with chronic diseases meant living with a significant amount of pain, either physical or emotional. Members from the South Asian community contextualised their experience of pain with reference to physical aches or soreness:

I wish my head would stop hurting (points to the back of head). That’s where it hurts (CDE-ATT-11, Female, Asian Indian, T2D and heart conditions).

headaches, at the back of my head, I would feel certain pains from the headache (CDE-ATT-12, Asian Pakistani, Female, T2D).

White British male individuals, in comparison, were less likely to make explicit references to pain or even use the term pain within their accounts. Experiences were interpreted through the changing capabilities of their body and how they wish to continue and complete tasks without the help of others:

If I go for a shower I get severe back ache when I seem to bend. Then I have problems with dressing myself but I do, do it because I want to do it, I don't get no help because I want to do it, I do it in my own time (CDE-ATT-17, Male, White British, multiple conditions).

This male interviewee continues his account, explaining his pain is constant and ultimately influences his ability to complete everyday tasks, hence, affecting his ability to 'cope' with chronic conditions:

the body can cope with it but the body can only cope with so much and that's what it's done with me, it's only coped so much and its turned around and said, "I'll start giving you pains now" (CDE-ATT-17, Male, White British, multiple conditions)

Black Caribbean participants made very few remarks about living with pain and felt much more confident about dealing with emotional distress. However, it remains difficult to comprehend whether members of this community were less emotionally affected or consciously avoided moments thinking about the possibility of deterioration in their condition:

I have not seen any changes because from the day of diagnosing to now, I've been taking the same medication: no increase, no decrease; it's the same ... But I don't sit around and feel sorry for myself. I don't let the condition manage me. I manage my condition. I live with it. So I do what I have to do (CDE-ATT-04, Female, Black Caribbean, T2D).

it don't help to moan, moan for what, no count your blessings... that won't stop me from doing what I want to do, it's just one of those things...(CDE-ATT-10, Female, Black Caribbean, T2D).

7.4.5.2 The role of religion in self-management

Religion played a key role when managing emotional well-being regardless of ethnic group or religious affinity. For Black Caribbean participants religion, Christianity, helped to ease anxieties and worries:

So I was saying to myself, "If the Lord said to cast your cares upon him", just cast it on him and you don't want to worry. You don't have to think about anything else (CDE-ATT-06, Female, Black Caribbean, T2D).

Not dwelling on problems was also present with members from the Sikh community. Sikhs believe thinking about your self can lead to feelings of pride/egotism and Sikhs should attempt to be selfless in their actions. Hence, keeping active was essential to not thinking:

Well when you are outside your mind is occupied, when you are sitting alone then you start thinking, “Why I had this heart attack?” (CDE-ATT-18, Male, Asian Indian, heart conditions).

For Sikh women, religious beliefs not only influenced emotions but other health-related behaviour. Sikhs are expected to follow a vegetarian diet with many incorporating a strict lacto-vegetarian diet (no meat, poultry, fish or eggs but dairy products are permitted). The following participant feels as if she needs to justify why she never followed vegetarianism:

[Interviewer] Why did you stop eating meat?

[Respondent] Just, I didn't want to anymore, I used to have it before a little bit, but now I will only have it rarely, but if I do eat it what's wrong with that (CDE-ATT-11, Female, Asian Indian, T2D and heart conditions).

For the Sikh cohort of my sample (N=5), their interpretation of emotional feelings was bound by a cultural and religious understanding of presenting emotions. The heart is interpreted as one of the most important organs within the body, as it is considered the source of strength and location for emotional understanding of social events. When an individual makes a reference towards the heart, the person provides a psychosomatic statement linking physical experiences of the heart with social experiences of stress. One Sikh participant expresses how she feels about her condition by reference to attending the funeral of a friend:

I never had the urge to cry, you know the *dil, delkran lag ghia, dil bachda si* [heart, it started to beat faster, my heart was beating] (CDE-ATT-11, Female, Asian Indian, T2D and heart conditions).

For Muslim participants religion played a direct role on their health-related behaviour. For example, a Bangladeshi participant expressed the importance of fulfilling fasting commitments even though going without food can be dangerous for those suffering from diabetes. This participant faced the obligation of practising appropriate health behaviours or his faith:

Yes, Ramadan, yes I was very good, my sugar never became low. I kept my *roza* [fasting/fasting commitments], I always keep my *roza*. (CDE-ATT-19, Male, Asian Bangladeshi, T1D and heart conditions).

None of the White British interviewees made any references to religious beliefs and the way they managed their illness. However, they did express feelings such worry and anxiety when they were first diagnosed as they knew little about their diseases. Greater information from health professionals and the CDE programme helped to alleviate such feelings.

7.4.5.3 Gender and identity

Participants' interpretation of their perceived social roles differed according to gender. Significant areas that influenced male identity were the inability to work and maintain a prominent role within the family, and alcohol consumption (with the exception of Muslim

participants). The inability to maintain paid employment meant male participants could not fulfil the role of 'breadwinner' which caused a greater amount of stress within the family:

She [participant's wife] knows I'm not going to get another job, because of my illness, then she gets stressed out and I get stressed out, and then we find out we're arguing at the end of the day over stupid things and we never seem to come to a compromise on these problems that we have in the house (CDE-ATT-17, Male, White British, heart condition).

It was just a great big shock that hit me worst of all, more than having cancer, leukaemia, ... me packing up work, that was jaw dropping, that hit me more than anything else (CDE-ATT-08, Male, White British, multiple conditions).

South Asian males also conformed to the 'breadwinner' role; however, maintaining employment was not based on acquiring an income but a demonstration that the illness had not taken away a core element of male identity:

When my son ask me, Dad, leave work, leave work, all the time, but it's in my blood, since the age of eleven I start working with my grandfather, since ... carry on, I work here [England] seven days all my life, so it's like alcohol [an addiction]. I can't leave work (CDE-ATT-18, Male, Asian Indian, heart condition).

With the exception of Asian Muslim males, drinking alcohol was also an important characteristic with regard to maintaining a strong male identity. Although some male

participants spoke of reducing their consumption, others continued to drink and opted to make other 'sacrifices' in their lifestyles:

There's no doubt about it that it's a macho thing. With me it was because I had such a terrible, terrible adolescence, crippling, crippling shyness, where other kids were meeting girls, I was absolutely terrified ... that fear has stayed with me to a lesser degree all my life, and I know I'm a more confident, relaxed person when I'm drinking than when I'm not drinking ... there's no doubt about it that's what it is, a prop, an addictive prop (CDE-ATT-20, Male, White British, T2D).

he (father) worked where it involved manual work and he always had two pints of beer when he came home and he didn't have sprits very much, so I would imagine that would have an influence, so follow suit (CDE-ATT-16, Male, Asian Indian, heart conditions).

Women's interpretations of living with chronic conditions centred on their perceptions of physical shape: trying to maintain a slim figure and attempting to lose weight. Maintaining a healthy weight was medically and socially interpreted, as losing weight would help to manage illnesses better and avoid the social stigma of being overweight or obese:

they said at the surgery that I'm obese, I said "Oh God, I don't want to be obese" [laughs], so I'm trying to lose it (CDE-ATT-13, Female, Asian Indian, heart conditions).

well since I've been diagnosed as a diabetic I know I've got to lose weight, I know I have, I'm struggling, I'm up and down, up and down but that's my own fault, but each time I eat something... I don't think of my diabetes (CDE-ATT-09, Female, White British, T2D and heart conditions).

Hence, regardless of ethnicity, female participants preferred to have or maintain a slim figure. This differs from existing literature which argues females from minority-ethnic communities born outside of the UK would prefer a larger figure compared to White British women (Bush *et al.*, 2001). Nonetheless, cultural interpretations of being overweight were similar; a large figure was associated with being idle, therefore, it was imperative to be responsible and manage diseases appropriately:

But if you are diabetes [sic] you must be serious you know, you know there are things you shouldn't have (CDE-ATT-10, Female, Black Caribbean, T2D).

Participants' accounts were also structured by age. Older participants (70 years and older) had experienced social exclusion exacerbated by physical limitations caused by chronic conditions:

We haven't actually got a social life at all, we spend most of our time in the house (CDE-ATT-08, Male, White British, multiple conditions).

White British participants considered the workplace as a site for social interaction where they would often socialise with colleagues after work. Individuals who were not retired were aware

their conditions would most likely prevent them for gaining further employment and therefore social interaction was limited:

sometimes it upsets me because I'm out of work, when I try to look for a job, I can't do this, I can't do that, because it's sitting down, picking up stuff and that (CDE-ATT-17, Male, White British, heart condition).

7.5 DISCUSSION

7.5.1 Interpretation of findings

Understanding the role of lay educators was important for participants, as it influenced the type of role they adopted within workshops and their interpretation of the CDE programme. The relationship between participants and CDEs was contextualised and understood in relation to perceptions towards the quality of care they expected to receive from health professionals. Specifically, participant perceptions were based on particular issues with their GP; providing brief consultations with limited regards to non-clinical issues. For many, this may have been the first time they acknowledged shortfalls in the quality of care they received from health professionals as they could compare service delivery provided by CDEs (albeit in a health education intervention). As a result, the relationship was performing a core aspect of their perceived ‘doctor-patient’ relationship; an on-going personalised therapeutic relationship based on listening and allowing the patient to have a greater say in their treatment (Guthrie and Wyke, 2006).

The group-based format of the programme allowed participants to share personal experiences of living with chronic diseases but were unstructured and without a specific goal in mind. In comparison, Greenhalgh and colleagues (2005) ‘sharing stories’ intervention had a clear focus on a topic of discussion (medication), participants sharing problems (specific issues with taking a combination of drugs), identification of common problem (group members not taking medication), and an outcome (telling GPs about non-concordance and GP informing participants how to deal with side effects from drugs). According to Greenhalgh *et al.* (2005; Greenhalgh, 2001) group participation should not only be based on knowledge acquisition, but allowing participants to negotiate the meaning of knowledge and prompting action.

Despite the aforementioned benefits of ‘sharing stories’, Greenhalgh *et al.* (2005) reported only modest improvements in clinical outcome measures compared to standard group education.

In addition, Cox (2001) argues that stories reveal worlds that are otherwise closed to us, such as those of the sick or physically impaired. These narratives do not just describe the personal experience of living with an illness, but reveal embedded narratives of social networks, folk beliefs and cultural history (Skultans, 1998); all of which influence a person’s health-related behaviour. Therefore, sharing personal narratives should be recognised as a behavioural change tool; uncovering beliefs and attitudes that act as barriers to change and subsequently promoting appropriate action.

The lack of peer-to-peer learning begins to cast doubt over the advantages of group health education, and subsequently chronic disease self-management programmes. Some of the advantages of peer-to-peer learning are thought to be: peers are a credible source of information (Clements and Buczkiewicz, 1993), peers can act as positive role models (Perry and Sieving, 1993) and information presented by peers may be considered more acceptable compared to other forms of health education (Health Education Authority, 1993). In the CDE programme, participants’ understanding of credibility (with regard to health information) was influenced by status. The CDE had a higher perceived status within the group in comparison to peers based on the assumption CDEs would be adequately trained to deliver such an intervention.

Peers are also considered as suitable role models for patients poorly managing their illnesses. The lack of peer-to-peer learning may have been a result of the type of person accessing the programme. Participant accounts show the main objective of attending the programme was either knowledge acquisition or gaining confirmation that current practices were appropriate self-management practices. None of the participants expressed any notion of acting as a potential role model which others could follow. Furthermore, the use of role models or 'modelling', a central element of Bandura's (1977) social learning theory, can be effective in health promotion initiatives (Grossberg *et al.*, 1993), but requires reinforcement i.e. peers having continued on-going contact (Turner and Shepherd, 1999). Morgan and Eiser (1990) argue education from peers is valuable as they are most likely to share attitudes and values with other members of a group. In contrast, some participants in this study felt the experience of living with chronic diseases was unique where no experience can be exactly the same as someone else's; naturally, participants were sceptical about accepting peer information.

Overall, the process of incorporating and implementing behavioural changes was interpreted as a negative experience based on past experiences of practising restraint, self-control, and showing willpower. Lay educators should be trained to recognise how previous experiences of making behavioural changes can build a participant's confidence when making further changes. Furthermore, lay educators should help participants recognise the benefits and positive aspects of making and sustaining lifestyle changes. Even so, participants were clearly able to identify social barriers which influenced their ability to make behavioural changes, moving away from psychological interpretations of behavioural change. This highlights a need to recruit lay educators with an understanding of wider social constraints facing disadvantaged people from multi-ethnic communities. This notion is supported by Rogers *et*

al. (2005) who argues that health professionals may place greater importance on scientific evidence and not engage with aspects of self-care outside of their professional perspective.

Developing a greater social understanding also relates to an individual's interpretation of health and well-being, as it often differs from those in a professional capacity (Cameron *et al.*, 2006). This interpretation of health and well-being is often contextualised through social factors. For example, a lack of suitable transport can mean spending greater time at home and the possibility of developing symptoms associated with poor emotional well-being, not having paid employment is a barrier to buying food to stay healthy, or a lack of local leisure facilities can contribute to an individual's physical well-being (Parry *et al.*, 2007).

7.5.2 Cultural adaptation

7.5.2.1 Adaptation to content

Analysis of participant accounts has shown that people from certain ethnic communities have different learning requirements and skills they wish to develop. Findings from South Asian interviewees support conclusions drawn in the previous chapter that members of this community show lower baseline knowledge of health information and are most likely to benefit from knowledge acquisition in comparison to members from the White British and Black Caribbean population. A review by White *et al.* (1998) investigating the effectiveness of interventions to promote healthy eating in people from minority-ethnic groups found behavioural modification was more effective in European origin (White) groups compared to minority-ethnic groups. In addition, the review recommended tailoring interventions for specific ethnic sub-groups.

Consequently, chronic disease self-management programmes should alter content for specific ethnic sub-groups. Interventions accommodating South Asian groups should concentrate on disseminating information about choosing healthy foods, the benefits of exercise and coping with emotions. Interventions accommodating White British and Black Caribbean groups should place greater focus on helping participants to make behavioural changes and how they may be sustained. Although, all ethnic sub-groups would require both health education and support making behavioural changes but may initially require different levels of support for each.

7.5.2.2 Adaptation to delivery

Recruiting lay educators from the community had the greatest impact on members from the South Asian population. Having a shared language, religion or ethnicity creates an impression of ‘resemblance’ between healthcare provider and patient (LaVeist *et al.*, 2003; Shaw, 2010). South Asian participants who attended the CDE programme benefited from improved communication while Black Caribbean and White participants benefited from establishing close ‘family’ like relationships. Ethnic concordance is thought to reduce the potential for power disparities between patient and health care provider, consequently patients becoming more involved in the decision making process (Krieger *et al.*, 2005). Yet, in this programme ethnic concordance had little or no difference with regard to participant involvement, particularly with South Asian participants who remained and preferred to be receptive.

7.5.3 Revisiting the literature: Originality of findings in this study

A central feature of CDSMPs is the role of peer-to-peer learning; patients helping each other to better manage their chronic diseases (Lorig *et al.*, 1999). However, findings in this study

have shown participants are critical of information given by peers and place greater value on information given by lay educators which they perceive as trustworthy. Lay educators should be trained to engage participants in conversations with each other whilst being readily available to intervene to confirm appropriate self-management practices and highlight inappropriate practices.

CDSMPs, in their majority, provide content and support on a number of areas concerning self-management: diet, exercise, emotions, information about chronic disease and communicating with health professionals (Lorig *et al.*, 2005). Analysis of participant accounts has identified that participants also require support dealing with issues regarding self-identity. CDSMPs designed for multi-ethnic populations should be tailored to inform participants how to manage with issues such as weight gain, social isolation and loss of employment.

Participants' reasons for the cause of their illness ranged from emotional, lifestyle and genetic factors, all of which relate to existing literature (Nazroo, 1997). However, participants who identified lifestyle factors as the primary cause of their condition cited a greater level of responsibility for changing their existing behaviour. This differs from current literature, as a recent paper by Lawton and colleagues (2007) found Pakistani and Indian respondents tended to externalise responsibility (i.e. life circumstances and experience of migration), and White respondents, by contrast, emphasised their own 'personal failings'. The difference in findings could be explained by religious status. There were, relatively, more Muslim participants in Lawton *et al.*'s (2007) study compared to my own; a group which is more likely to hold fatalistic beliefs and sentiments of helplessness (Johnson *et al.*, 2000) compared to Sikhs, who comprised the majority of my South Asian sample. This is important in terms of cautioning

against assuming all non-White groups have similar experiences and attitudes, which is often done.

7.5.3 Strengths and limitations

Data were collected from a diverse sample of different ethnic and religious groups, male and female and living with a range of chronic diseases. Participants with language requirements were included within the sample (Punjabi, Bengali and Urdu speakers). Interviews covered a wide range of topics, ranging from describing the group experience to living with chronic diseases; an area rarely covered in the evaluation of chronic disease self-management interventions.

There were a number of limitations. Participants, in their majority, came from courses delivered by three CDEs. For some interviewees there was also a considerable amount of time between completing the course and conducting the interview which inevitably affected what participants could remember about attending the programme. However, the greater amount of time between the end of the programme and interview helped to distinguish which information/part of the programme participants remembered and incorporated in their lifestyle. The sample of participants recruited (N=20) was quite considerable for a qualitative study. Interviews were rich in detail, covered a range of topics and reinforced findings generated from data collection using other methods and participants.

7.5.4 Future research

Recommendations for future research are presented in Chapter 9, but those originating from findings in this chapter are presented here. In relation to the development and design of

chronic disease self-management programmes, further research is required to understand the learning needs of different ethnic groups and sub-groups. For example, there is uncertainty which format; group, one-to-one, or family-orientated interventions are effective for at risk minority-ethnic groups. Also, greater attention on understanding the health needs of men suffering from chronic conditions is needed. Studies from the systematic review (Chapter 3) showed certain activities, such as cooking demonstrations, may not interest men and therefore increase the likelihood of attrition or non-completion. Further exploration is required to see if men would be more likely to attend and complete chronic disease self-management interventions if they covered areas synonymous with male identity, such as alcohol consumption, coping with physical restriction/impairment or dealing with the loss of employment.

The majority of non-White participants from my sample were born outside of the UK; i.e. first generation migrants. Given that a number of the cultural adaptations made to the CDE programme were designed to accommodate individuals born outside of the UK, a greater understanding of the health needs of second and third generation descendants from at risk groups is needed. Specifically, more needs to be known about how health services should be designed to accommodate their needs. This is explored further in the next chapter; investigating health beliefs, in relation to chronic disease and self-management, across three generations of the Sikh community.

7.6 SUMMARY

In this chapter, I presented themes generated from the analysis of interviews conducted with participants completing the CDE programme. Findings varied according to context: age,

gender, ethnicity, religion and illness. There were a number of findings. Participants and lay educators were able to establish strong trustworthy relationships within a relatively short space of time. This relationship addressed aspects of care left unfulfilled by GPs.

The experience of attending the CDE programme differed for South Asian and non-South Asian groups. South Asian participants were much more likely to report gaining new knowledge compared to Black Caribbean or White British individuals, who wished to gain confirmation that their existing practices were appropriate to self-manage their chronic diseases. Members of the South Asian community, overall, expressed positive attitudes towards cultural adaptations. Participants appreciated the fact that CDEs were recruited ‘from their community’ and who addressed their linguistic communication needs. However, apart from meeting linguistic needs, it remains uncertain whether participants benefited from ethnic concordance with CDEs. Finally, a number of reasons were cited as the potential cause of chronic diseases. Interpretations of causation were entwined with feeling of personal responsibility about making lifestyle changes. Nevertheless, some participants expressed an externalisation of responsibility highlighting social constraints and government legislation as factors influencing health related behaviour.

In the following chapter I present findings from data collected with the Sikh community. The chapter is intended to be explorative rather than a factual representation of health beliefs. I explore the importance of ‘systems of support’ for those living with or at risk of developing long-term conditions. The following chapter leads on from themes identified from this chapter, further investigating the relationship members of the Sikh community have with

professional/lay health services and how different aspects of living with chronic diseases are interpreted.

CHAPTER 8

8.0 UNDERSTANDING CHRONIC DISEASE AND SELF-MANAGEMENT IN THE SIKH COMMUNITY

8.1 INTRODUCTION

This chapter presents findings from the exploration of health beliefs, in relation to chronic disease and self-management, across three generations in the Sikh community. The chapter begins by discussing the systems of support framework, developed by Rogers *et al.* (2011), which has been used to interpret findings. The framework was used to critique the systems of support that exist in the management of long-term conditions, and the enabling and constraining properties within lay and professional health systems. Findings are presented in two sections: a description of systems of support and their functions and the enabling and constraining properties of each system of support. A summary is provided at the end of the chapter.

8.2 BACKGROUND

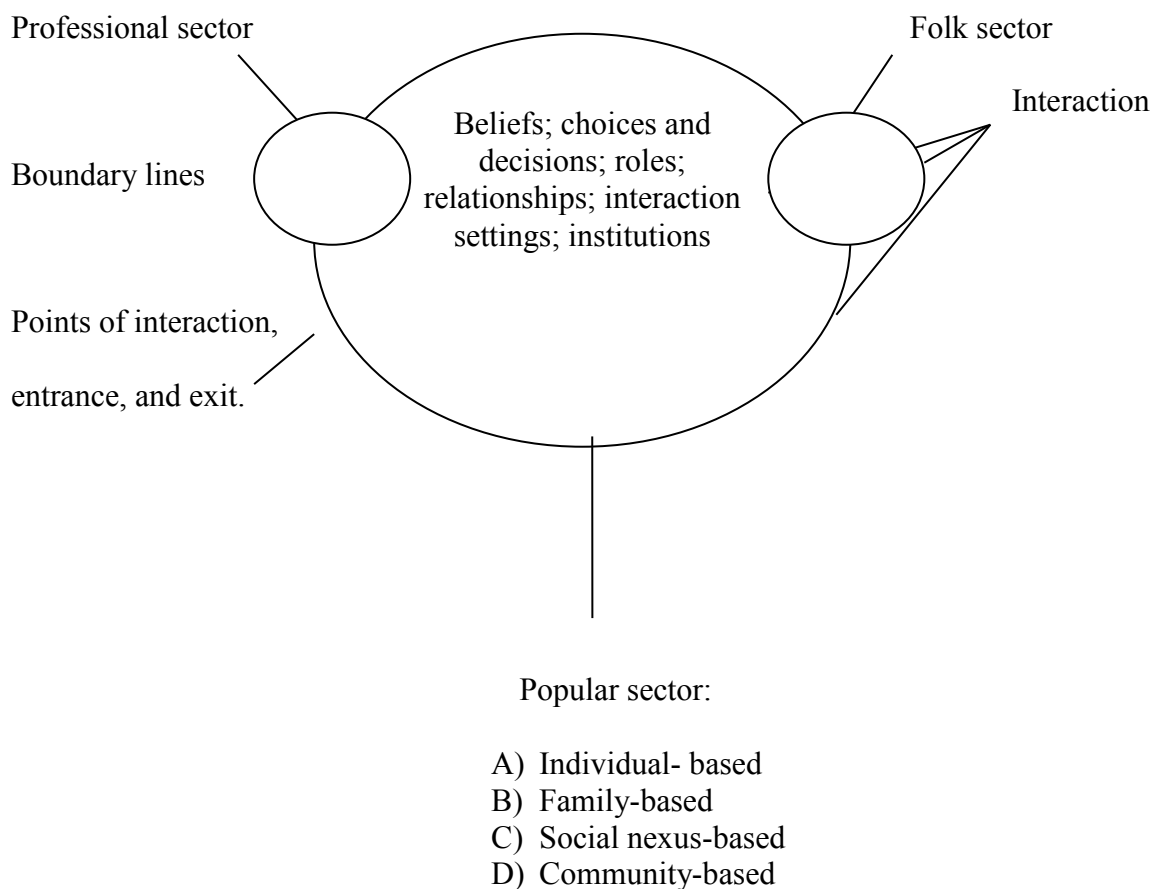
8.2.1 Health systems as cultural and social systems

8.2.1.1 The Kleinman (1978) model

Understanding systems of support begins with interpreting medical systems as cultural systems. Kleinman (1978) provides a model to understand health, illness, and healing within society as a cultural system, and compares such systems cross-culturally (pg. 85). Medical systems are not only cultural systems but social systems where meanings and norms are attached to particular social relationships and environments. Kleinman (1978) presents a health care system with three social arenas: *popular*, *professional* and *folk* (Figure 14). The

model was used to interpret medicine in the Chinese culture, comparing professional scientific (Western) medicine with professionalised indigenous healing traditions.

Figure 14: Kleinman (1978) Health care system: internal structure (adapted from Chinese culture and medicine)



Pappas (1990) criticised this model, and other medical anthropologists, for focusing on agency and de-emphasising the importance of structural institutions in health care decisions. The model also over-emphasises the significance of communication between patients and practitioners, whether it is health professionals or traditional healers. McKee (1988) argues holistic approaches to health and well-being focus on the 'totality of the individual'; a holistic

approach which fulfils the needs of the individual rather than altering the social structure that promotes an ‘unhealthful’ environment (pg. 775).

8.2.2 Rogers *et al.* (2011) systems of support framework

The systems of support framework is intended to increase the effective targeting and promotion of self-care support for people suffering from long-term conditions. The approach endeavours to understand the mobilisation of resources beyond health professionals and the network of relationships: individuals with other individuals, and individuals and communities (Rogers *et al.*, 2011: 56).

Rogers *et al.* (2011) argue current psychological approaches fail to recognise the importance of the social context in which self-management occurs. They argue that greater attention needs to be given to individuals and systems of support that go beyond the individual to include personal communities (e.g. family), community groups, non-health professionals, and health professionals (Rogers *et al.*, 2011: 57).

8.2.2.1 Social networks, social capital and chronic illness self-management: a realist review

The systems of support model draws on an evidence synthesis conducted by Vassilev *et al.* (2010). The review identified 61 papers through systematic searching. The types of networks identified were: networks as relationships (a set of dyadic relationships that are independent of each other); networks as affective communities that can be comprised of pre-existing communities, e.g. religious and/or ethnic groups; and networks that are part of larger networks i.e. personal communities.

The review concluded different networks have different functions. Each function shapes the structure and nature of interactions within networks and the relationship professional (i.e. health professionals) and non-professional (i.e. traditional healers, family) networks have with each other. Professional networks, in their majority, were based with the individual at the centre of relationships while non-professional networks had a much more complex set of social relations and utilised less by individuals.

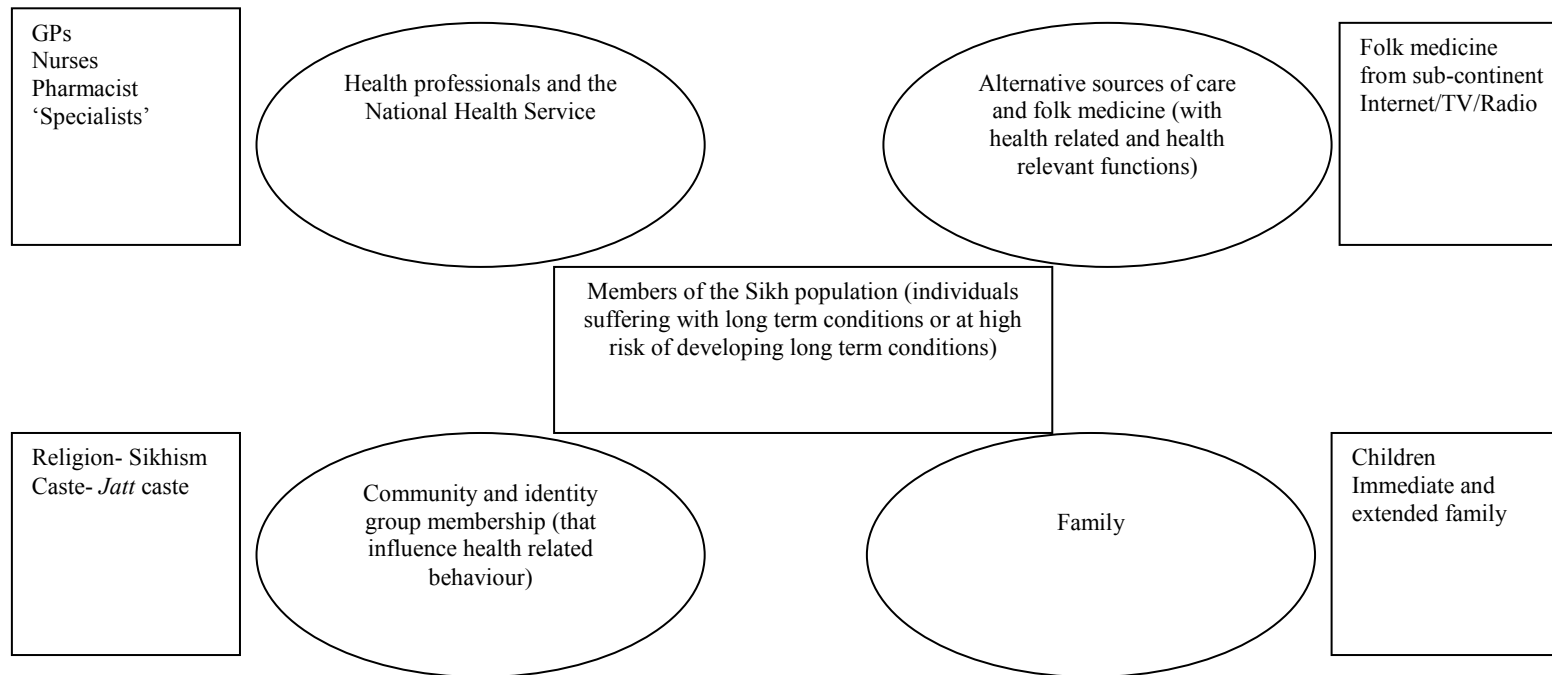
8.2.3 Application of the systems of support framework

The findings presented in this chapter are not a replication of Rogers *et al.* (2011) methods, as data were not collected with the framework in mind. My intention of using the framework is to understand the role and engagement participants have with systems of support. In contrast to Rogers *et al.* (2011) research, my interpretation has centred on the term ‘systems of support’ rather than ‘social networks’. The intention was not to concentrate on the connections between individual actors, the aim of network analysis (Marin and Wellman, 2011), but recognising the types of self-care support provided by each system from an individual and community perspective. Relations within systems of support have been interpreted using the term ‘ties’ to indicate whether support is going from one person to another or whether there is no particular direction of support (Marin and Wellman, 2011: 20).

The core strength of the framework is the emphasis on patient and social context, identifying ways self-care support can be integrated into people’s everyday lives. Hence, the framework has been used as a tool for interpretation and to extend the theory presented by Rogers *et al.* (2011) to the Sikh population. Figure 15 demonstrates the application of the systems of support model in the Sikh community. Participants referred to the same broad four

categorisations of support but the function, relationships and properties that existed within each system differed.

Figure 15: Systems of support for the management of long term conditions (LTC) in the Sikh community



8.3 CHARACTERSITICS OF PARTICIPANTS

8.3.1 Participant demographics

The demographic details of participants recruited from the Sikh community are presented in Table 24. A total of seventeen participants were recruited and interviewed from the Sikh community residing in Birmingham and the Black Country (Cape Hill, Oldbury, and Wolverhampton). All eight first generation participants were non-bilingual and only spoke Punjabi, while the remaining nine participants (second and third generation individuals) were bi-lingual and spoke both English and Punjabi. In order to gather a greater understanding and provide context to my analysis, interviews were conducted with a community pharmacist and two people who held executive positions in different Sikh temples in Birmingham and Wolverhampton.

Table 24. Participants recruited from the Sikh community

Demographic details	Number of participants
Members of the Sikh community	17
First generation (born in the subcontinent)	8
<i>Age range</i>	47-77
<i>Male/Female</i>	2/6
<i>Occupation</i>	Retired (4), Manual (4)
<i>Chronic diseases</i>	Diabetes (Type 1 and Type 2), Hypertension
Second generation (born or received formal education from the age of five in the UK)	7
<i>Age range</i>	18-43
<i>Male/Female</i>	4/3
<i>Occupation</i>	Student (2), Manual (2), Professional (3)
<i>Chronic diseases</i>	Type 2 diabetes, Hypertension
Third generation (born in the UK and at least one parent is second generation descendent)	2
<i>Age range</i>	20-24
<i>Male/Female</i>	0/2
<i>Occupation</i>	Student (1), Professional (1)
<i>Chronic diseases</i>	None

8.4 DESCRIPTION OF SYSTEMS OF SUPPORT

8.4.1 Systems of support

Each system of support served a particular purpose which resulted in four different functions with regards to management. The functions were not mutually exclusive, with some systems providing more than one form of management. The four different functions, with regards to the Sikh community, are extended from Rogers *et al.* (2011), where every day self-management is further categorised into symptom, lifestyle and emotional management, while disease management remains the duty of the formal health system and health professionals:

1. Health professionals and the NHS provide support for disease management
2. Alternative sources of care and folk medicine provide support for symptom management (i.e. symptoms associated with chronic disease and general ill health)
3. Community and identity group membership influence lifestyle management and changes
4. The family provides support for emotional management

8.4.1.1 Health professionals and disease management

Health professionals and the NHS covered a range of functions providing consultations, being a source of readily available health information, referring patients to secondary care and prescribing medication. Participants varied in their attitudes towards health professionals (general practitioners, nurses, pharmacists and specialists), especially general practitioners (GP); the most utilised health professional. Participants from all three generations felt the GP was an 'expert': an individual who is knowledgeable and provides definitive answers to medical concerns:

if I had a condition and I was thinking that I wasn't too sure about it, what is it, I would probably research it and then I would probably book an appointment with my doctor and say look I researched this, is it correct? (Participant SK-01, Female, Third Generation, 20).

She [GP] makes a note and she might change my medication, increase or lower the dosage (Participant SK-20, Female, First Generation, 68).

Searching health information without medical guidance is compared with the expertise and trustworthiness of the GP. Identifying health information in isolation is unlikely to displace health professionals, when dealing with issues relating to disease management. The health professional system is constructed of directed ties based on value; the relationship is determined by resources (health advice and/or medication) given by the doctor to the patient, which is not reciprocated. Therefore, the contribution made by the doctor is perceived to be of higher value compared to the contribution made by the patient. As all first generation participants in the sample were non-bilingual, an important group in this system were relatives (children or grandchildren) who acted as translators and advocates; speaking on behalf of their relative so their views are put forward:

when I go to the doctors with my grandmother, if I go with her I can have that conversation with him [GP], and my grandmother is being informed and part of that conversation, because I make sure that it's not done in isolation, without her, whereas if she goes by herself she could come out with a very wishy-washy response (Participant SK-02, Female, Third Generation, 24).

The intention of advocates was to make non-bilingual older individuals part of the consultation process. Consultations between bi-lingual health professionals and first generation individuals were characterised by passivity and docility, with health professionals directing the nature of interactions and decision making process, a feature a number of participants appreciated:

Our doctor was very good, he would always prescribe me very good medicines, Dr [name removed], he would be straight to the point, he would give us our medicine and we would accept it and remain quiet, he would tell us what tablets to take, we would take them and we would feel better (Participant SK-19, Female, First Generation, 65).

The aforementioned participant describes a traditional doctor-patient relationship. The relationship is based on treating the illness/disease alone and removes all consideration of social implications. In consultations, either with advocates or bi-lingual health professionals, first generation participants adopted a receptive position: kept informed of the decision making process rather than playing an active decision making role.

Second and third generation participants had expectations of a health service that followed a ‘consumerist ethos’: the desire to be treated quickly and having greater involvement in the decision making process. The concept of time was central to participants ‘consumerist ethos’:

sometimes your stress levels can make yourself ill because you’re just working yourselves up waiting around because I’m a very impatient person so I just don’t like

all the waiting around. Time is really important (Participant SK-06, Female, Second Generation, 42).

‘Time’ often related to participants’ perception of the availability of services and how quickly they could access services in the event of having a pressing concern for their health. Second and third generation individuals placed a greater importance on having their needs addressed rather than on who was addressing them:

with the drop in centre you’re straight in and immediately you’re checked, you’ll have someone there, you’ll know there you will be seen rather than waiting a couple of days, so you will be seen within the hour or two, so that’s better (Participant SK-07, Male, Second Generation, 22).

Second and third generation participants presented a desire to be treated quickly and have greater involvement in the decision making process. This was demonstrated by participants’ greater knowledge (in comparison to older, first generation participants), apparent comfort in questioning their GP, a desire for control and autonomy, and the doctor acknowledging their contribution in the consultation process. The following participant explains the difference between her own consultations compared to her grandmother’s:

I would feel more comfortable and confident positively challenging my GP if I wasn’t happy or comfortable with the service I was getting, but I find his approach with me, when I’ve been to him is completely different. He’s a lot more comprehensive in his

answers, he'll give me a lot more detail around what he thinks... (Participant SK-02, Female, Third Generation, 24).

Although second and third generation participants appear less reverent towards their GP, it remains difficult to determine whether younger participants would still be as challenging of the GP's expertise if they suffered from a complex chronic disease(s).

Older people still expected health services to be delivered in a culturally sensitive manner. First generation participants valued health professionals, often from the same or similar community, who demonstrated cultural application by using particular terms to address participants, such as '*Bibi*' [grandmother] to refer to older women:

like my doctor, she's Punjabi, she speaks Punjabi and she understands everything I say. When she gives me medicine she will ask '*Bibi Ji*' what hurts, why do you need medicine?' and I can tell her everything. She makes a note and she might change my medication, increase or lower the dosage, but she understands Punjabi, she speaks it, and she's one of our own (Participant SK-20, Female, First Generation, 68).

Finally, members of the Sikh community felt disease management should remain in locations primarily designed to address peoples' health concerns i.e. the GP surgery. Participants felt a 'controlled environment' such as GP surgery was suitable as the patient would be aware of the purpose of their visit:

The GP setting is a much more controlled environment. I think you can run fantastic clinics there because you're telling the patient what to do before they come in, you say you need to fast before you come in and check your blood pressure (Participant SK-03, Male, Second Generation, 39)

Not only was the GP setting a suitable location to manage an individual's illness, but it was a suitable location for first generation participants to readily gain access to health information:

When you go the doctors there are leaflets that we can read, the things one can practice to reduce their blood pressure, one should exercise... when you read things you understand that salt can increase your blood pressure (Participant SK-14, Male, First Generation, 51).

8.4.1.2 Alternative sources of care and folk medicine provide support for symptom management

The system of alternative sources of care and folk medicine included herbalists, traditional healers, remedies from the subcontinent and the use of the internet. None of the participants cited using non-health professionals in a UK context, for example accessing lay health workers. However, one participant did refer to a group education programme her grandmother attended but was unable to confirm whether it was lay or professional led. Alternative sources and the internet provide supplementary medication and health advice relating to the management of symptoms associated with long-term conditions or ill health.

First generation participants were able to access health advice from herbalists and traditional healers from the subcontinent, via free-to-air television and radio stations. Information related to lay remedies originating from Ayurvedic medicine, also known as *desi* remedies, i.e. remedies created with natural ingredients found in the subcontinent:

I already practice most of the *desi* [Indian/ from India] remedies the doctors [traditional healers] on TV talk about, like cumin seeds being good for you, ginger being good for you, for our health, to prevent phlegm... (Participant SK-17, Female, First Generation, 70).

Interaction was not based on established relationships, prior contact, or face-to-face interactions, but the knowledge first generation participants had of herbal healers from the subcontinent prior to migration and on-going visits. In relation to the internet, again there was no face-to-face contact between individuals, and no established method of searching, with participants questioning the creditability of health information available. This led to second and third generation participants using GPs as a source of health information:

the GP is the main source of advice, the person who I talk to when I need to get advice (Participant SK-05, Male, Second Generation, 18).

Participants felt alternative medicine could provide relief from symptoms associated with living with an illness or chronic diseases, but first generation participants remained critical of foreign prescribers and health systems:

At least the medicines that are available here [UK] you think at least there're from England. You think that at least here there isn't that corruption. There is too much corruption over there [India] (Participant SK-19, Female, First Generation, 65).

The relationship participants had within the alternative sources system of support was based on distrust towards foreign medication, health systems and alternative support in the form of the internet. This relationship was often compared to the greater trust participants had towards their GP:

I can only gain relief if I go to the doctors, nowhere else, because I've never been to a homeopathic because they tell you plenty about them on TV, that this homeopathic gives this medicine but I don't think I will be able to gain relief (Participant SK-13, Female, First Generation, 70).

There are loads of symptoms flu could be for... so I'd rather get the expert to tell me than me telling myself. I might look on the internet just for knowledge but I won't get the right diagnosis because I'm not medically qualified (Participant SK-06, Female, Second Generation, 42).

The alternative system of support was only accessed when health professionals were unable to fulfil aspects of symptom management. The continued use of folk medicine, particularly amongst first generation participants, is a reflection of passing health beliefs from one generation to another:

whenever you see your elders they tell you about their ways, their *desi* remedies
(Participant SK-10, Second Generation, Female, 45)

8.4.1.3 Community and identity group membership influence lifestyle management and changes

The community-based system is characterised by collective cultural and social norms which influence individual lifestyles and the ability to make lifestyle changes. The system is based on a participant's ascribed membership to two specific groups: the Sikh community; and caste (a system of social stratification based on an ascription-based status prior to migration). The majority of individuals in the sample (N=15) were of the *Jatt* caste- individuals who have their ancestral origins either in the ownership or maintenance of agricultural land.

Membership of the Sikh community and caste groups are context dependent. For instance, individuals are much more likely to express their Sikh identity in a *Gurdwara* [Sikh place of worship] and a caste identity on social occasions. Sikhism rejects the existence of a caste based hierarchy but caste and caste values remain prominent among Sikh diasporas. The values and beliefs individuals from the Sikh community hold are not fixed but negotiated daily and are contextually dependent on physical space and their presence within certain social groups.

A particular method first generation participants' chose to express their membership to both the Sikh and caste groups was the consumption of traditional Asian diet; a diet based on foods from the subcontinent such as lentils, pulses, rice and chapattis. There was an absence of fish and/or poultry within a Sikh diet, because these are religiously frowned upon. First generation

participants felt a Sikh diet comprised foods that helped to maintain ‘good’ health, such as bitter melons that are perceived to help with the management of blood sugar levels for people living with diabetes:

With regards to eating, it depends whether they have sugar [diabetes] or anything else, blood pressure [hypertension]... eat lettuce, other vegetarian foods, vegetables, bitter melons, okra, *daahl* [curry] is also good (Participant SK-15, Female, First Generation, 77).

Greater satisfaction with an Asian diet was met, correspondingly, with dissatisfaction towards western meals; interpreted as convenience and processed foods that lacked nutritional value:

I don’t prefer dinners [western meals], what one may describe as the meals White people have, like our children will purchase things like pies from outside our home, things like sausage rolls, those things are heavy, they contain flour, it contains lots of oil, they contain rubbish (Participant SK-17, Female, First Generation, 70).

The perceived greater satisfaction towards Asian foods and corresponding dissatisfaction with western foods may reflect first generation individuals’ experience of migration and settlement in the UK. Although many Sikhs have experienced financial prosperity post migration their initial areas of settlement were likely to be deprived. The type of food readily available and consumed in such locations may have been high fat, convenience and/or processed foods. Therefore these foods have been interpreted as ‘Western’.

Second and third generation participants demonstrated greater levels of acculturation, reflected by their attitudes towards a healthy diet. Attitudes were based on the importance of different food groups, where a diet that included vitamins, minerals and was low in fat was preferred regardless of whether it was from an Asian or western diet:

something that has good carbohydrates, reasonable amount of protein, less fats, rice, potatoes, pasta. Some people have chicken, fish where you get the oils from, omega 3, 6, and 9. For me, we get [it from] *daahl* (curry) as well, so Indian foods we [have] soya beans, we get rice... (Participant SK-07, Male, Second Generation, 22).

Younger women from the Sikh community faced an expectation to conform to certain cultural values such as abstaining from eating meat and drinking alcohol, values the majority of first generation women adhere to. This is not uncommon in South Asian communities, as women are considered the bearers of cultural values. Women who undertook such practices were frowned upon by older members of the community:

Back in India women never ate meat, they would say that if you eat an animal then you are eating a person, that is when men ate meat and women couldn't, so they didn't want women to eat meat. Nowadays women eat more meat than men, they drink more alcohol than men, in past times which woman would drink? No woman would drink (Participant SK-17, Female, First Generation, 70).

Second and third generation women faced pressure to conform to cultural and religious norms and values determined by their membership of the Sikh community but also practices

established within a western country, where drinking alcohol was considered as prerequisite for gaining membership to 'liberal English' culture:

I don't think that drinking is seen as wrong, but to be honest within the second generation it's becoming the norm, but it's to what impact we drink, we work in a liberal English, well we're in a liberal English country where we don't have to drink but we're in an environment where we do have parties, we do have functions we do attend things where alcohol is there... and I don't feel as if I'm doing anything wrong (Participant SK-06, Female, Second Generation, 42).

Maintaining cultural values and lifestyle practices were dependent on physical locations and social groups participants were part of. When participants were with other Sikh individuals, it remained important to adhere to practices associated with a Sikh and caste identity. However, when second and third generation participants, found themselves in the presence of non-Sikhs, they experience conflict, whether to maintain or remove their religious or caste identity.

Participants also took greater responsibility for modifying behaviours. The practice of removing sugar from tea was well established in the Sikh community, where it had become common practice for tea to be drunk without sugar:

drink tea without sugar... first we ask whether one has put sugar in, if they have, then I won't drink it (Participant SK-20, Female, First Generation, 68).

A common health belief within South Asian communities is sugar being a cause or a contributory factor towards diabetes, therefore removing sugar from tea is a positive community-level established change. Nevertheless, it is still common to serve sweet foods alongside tea; therefore, the benefit of removing sugar from tea is reduced:

I clicked on one of these Facebook sites that I liked and on one of the sites there was something like ‘I will not have sugar in my tea but I will have three pieces of *baarfi* [Indian sweets]’ (Participant SK-09, Male, Second Generation, 51).

Even though members of this community have taken responsibility to make lifestyle changes, there are still opportunities to help individuals to implement behavioural changes more appropriately to aid self-management of chronic diseases.

Sikh families followed a traditional household structure where social roles were defined by gender and culture. First and second generation women played a significant role in the preparation of food, as they prepared the majority of meals. Women often determined the ingredients included in Asian meals, and whether oil or butter was used in preparation. The use of oil or butter carries cultural significance, as traditionally the use of butter is associated with wealth, esteem and honouring a guest’s presence within the home. The use of butter was disapproved of by younger second and third generation participants, where they actively encouraged parents to use oil instead:

everything she [mother] puts in, she’ll put in a quarter or half a slab of butter in it, to look at it, it doesn’t look a lot. I’ve changed her a little bit myself to use a little more

healthier oils but before she used to be terrible (Participant SK-06, Female, Second Generation, 42).

The use of butter or oil represents the extent to which a family adheres to cultural values and tradition, something that is expected from older members of the community:

in the past, when we would make spinach, our elders would tell us to place butter in, but nowadays I put oil in, but I don't tell anyone that I have put oil in (Participant SK-10, Female, Second Generation, 45).

Membership of the Sikh religion and certain caste groups form a contradictory relationship which influence lifestyle management: preference towards religious obedience while maintaining cultural values determined by caste. Caste influenced relationships in the community system of support, particularly male participants that belonged to the *Jatt* [agricultural ancestry] caste. Five out of seven male participants in the sample were of the *Jatt* caste in Sikhism. The practice of drinking alcohol and encouraging others to drink was seen as a practice that was well-known and established among *Jatt* Sikhs, where male participants felt they were obliged to provide alcohol to male guests even when they refused; a practice embedded in *Jatt* culture:

there is almost a *Jatt* culture where you have to have too much to eat and too much to drink and you have to force it down people's throats, but you don't see the same thing happening with some of the other castes (Participant SK-09, Male, Second Generation, 51).

The relationship male participants had with their caste identity conversely contradicted their membership and relationship to the Sikh community which strictly forbids the consumption of alcohol. One participant, of a different caste status, *Naam Dhari* (a group which believes living Gurus as well as the Sikh holy text, The *Guru Granth Sahib Ji*), presented a greater religiously defined stance towards the practice of drinking alcohol:

Sikhism should influence every aspect of your life, a person that eats meat and drinks alcohol, when that person prays or what we call *naam simran* [understanding ones purpose in life and their existence] then you begin to understand your own actions, holy scriptures do not allow this, that Sikhs partake in eating meat or drinking alcohol (Participant SK-18, Male, First Generation, 42).

The relationship participants had with their caste and religious identity is based on contradictions, influenced by caste values and religious approval. For *Jatt* participants, fulfilling their caste-based obligations were as important as fulfilling religious practices, as their roles of being a hospitable host was of great importance from a community perspective.

The *Gurdwara* [the site where Sikhs worship] represented the cultural and religious norms present within this community. The expectations to maintain cultural and religious values led participants to question the suitability of the *Gurdwara* with regards to delivering health services.

The suitability of using the *Gurdwara* was subject to practical and religious concerns. The *Gurdwara* addresses a number of practical concerns, as health services can be delivered in a

location that is familiar to members of the community, can accommodate a relatively large audience in a single location, and carries community legitimacy: members of the community feel the *Gurdwara* is a suitable location to discuss social concerns. Nonetheless, religious settings are unsuitable when practices go against religious doctrine i.e. alcohol abuse, therefore, the *Gurdwara* may only be suitable for health services targeted at the whole community rather than specific groups e.g. individuals who drink alcohol:

I think if you wanted to give information out about liver conditions, most of it is induced by alcohol so they wouldn't really talk about it in a *Gurdwara* because they would feel uncomfortable about it, because at the end of the day it is forbidden in our religion so you wouldn't really talk about it in a place where it is forbidden... confessing a big sin (Participant SK-07, Male, Second Generation, 22).

8.4.1.4 The family provides support for emotional management

The family system of support was based on immediate and wider kinship established by affective ties; relationships which are dependent on the feelings individuals have towards one another, established contact, and familiarity. The family, with regards to the Sikh community, refers to an extended family; family consisting of parents, grandparents, children and aunts/uncles living in one household or nearby. Participants described the primary function of the family is to provide emotional support during times of distress either caused by the inability to manage chronic diseases or personal issues. None of the participants in the study mentioned discussing personal and/or causes of emotional distress with individuals outside of their families. The cause of emotional distress was both internally interpreted (individuals attempting to answer why they have been diagnosed with an illness):

It was like I'm still really young, now at any time I could have a heart attack or stroke, so I could have a stroke, then you don't feel like eating any food, even when you look at food sometimes you feel guilty, you think why do I eat these foods, why haven't I become aware of this before (Participant SK-10, Female, Second Generation, 45).

For some, emotional distress was externally contextualised; the desire to maintain and help individuals who were part of their immediate kinship group:

constantly thinking, thinking about one child, then the other, and then the other and that's why they say that a person that does not think about others they are healthy, very healthy (Participant SK-15, Female, First Generation, 77).

The family system provides access to people that participants are familiar with, have empathy with cultural issues they experience and ensure confidentiality, dismissing any perceived fear of exposure. However, the family system is characterised by women seeking emotional support from other women. First generation women that were married had a greater number of relations and roles in their kinship network, where younger unmarried women cited fewer. Thus, married women were expected to maintain ties with their family of birth and new families post marriage (i.e. in-laws). As a result, unmarried women developed coping mechanisms that could be used in isolation, such as prayer:

I generally prayer every night... and it makes you feel, yeah I'm gonna be ok (Participant SK-06, Female, Second Generation, 42).

The family also provided physical care, as children, usually daughters, played a significant role in the day-to-day self-management of older relatives living with chronic diseases. Second and third generation interviewees expressed a sense of duty to provide physical care for older relatives, met with first generation participants' expectation:

It's the children's responsibility, it's my girls responsibility, make phone calls, write down my prescriptions and collect them, to take me to appointments (Participant SK-20, Female, First Generation, 68).

obviously we try and help one another... perhaps I've got to do a few more things and cautious about what my Nan's eating (Participant SK-01, Female, Third Generation, 20).

The family system of support was characterised by a limited number of people, where family members would access emotional support from the same people repeatedly. Participants expressed considerable periods of isolation prior to communicating emotional distress with close others. Emotional distress was presented psychosomatically, where culturally-bound experiences of distress were interpreted through references to the heart:

It could be from work, family stress, there's always something happening, they might be smiling to other people but you can never know what's happening on the inside, what's in their heart (Participant SK-10, Female, Second Generation, 45).

First generation female participants continued to express feelings of emotional distress through their experience of living and coping with a chronic illness. This led to questions about physical care; participants felt it was inevitable they would become increasingly dependent on other family members to fulfil everyday tasks on their behalf:

I can't do anything, like now my joints are swollen, sometimes I struggle to open the top of a milk bottle, sometimes when I can't do these things I think I would be better off in a [care] home... I can no longer do anything so at least someone will help me (Participant SK-15, Female, First Generation, 77).

There was an expectation members of the family would take the increased responsibility of physical care, where culturally it would be children who took on the additional responsibility rather than spouses.

Individuals across all three generations recognised exercise as an important part of their lifestyle which benefited their emotional well-being:

Being active keeps you mentally and physically sound, being physically active helps your muscles and your body to function properly and being mentally sound is important too, to cope with everyday stresses and pressures (Participant SK-05, Male, Second Generation, 18).

There were generational differences with regards to where exercise was conducted; either inside or outside the family home. First generation participants preferred to exercise within their homes in isolation, identifying household tasks, such as gardening, as physical exercise:

I'm going to do some digging in the garden with a shovel, that's exercise as well, so dig the whole garden with a shovel, press in into the ground with your foot and rip it all up. This is exercise, all of this heavy work (Participant SK-13, Female, First Generation, 70).

Conversely, second and third generation participants demonstrated a greater preference for group-based activities, with participants comparing the experience of going to the gym with sports that can be done with others outside of the home:

I do like going to the gym but I'd rather play sports like badminton, like once a week, or I'll try and play football or something once a week where you have somebody else there with you (Participant SK-01, Female, Third Generation, 20).

8.5 THE CONSTRAINING AND ENABLING PROPERTIES OF SYSTEMS OF SUPPORT

8.5.1 Constraining and enabling properties

8.5.1.1 Health professionals and disease management

A significant barrier first generation individuals faced was the inability to communicate with health professionals providing support for disease management. 'Good' communication was understood from two different standpoints: 'linguistic' communication, the ability to speak

with health professionals in a single, common language; and ‘conceptual’ communication, whether the health professional is able to understand the context of the patient’s symptoms and the ability to listen to their concerns. The unavailability of health professionals with ‘good’ communication skills gave non-bi-lingual first generation participants the difficulty of arranging a suitable interpreter:

I can't speak English completely, I can only speak a little, I can speak to get by but not completely, but if it is a complicated pain I can't describe it and I also find it difficult to respond so that is why I take her [daughter] along. Previously I would just go by myself and tell [son's name removed] to arrange an interpreter... (Participant SK-15, Female, First Generation, 77).

Participants’ expectation of a ‘good’ communicator involved the health professional easing the patient’s anxieties, providing a thorough and understandable explanation and listening carefully to the patient. The role of a ‘good’ communicator should also include a professional, yet personable demeanour such as being polite, respectful and courteous. For some, a personable demeanour transcended issues of ethnic concordance:

the doctor is a doctor whether it is one of our own, a White person, a Black person, that makes no difference...they become friendly, like a member of your household (Participant SK-04, Female, First Generation, 56).

For older members, being treated by a health professional who can communicate in Punjabi makes it easier to explain and present one’s symptoms without the presence of third parties in

the consultation. Health services delivered by health professionals from the ‘community’ (the South Asian or Sikh community) enabled participants to build stronger relationships with health professionals, enhancing both linguistic and conceptual communication:

the greater the number of our own people who work in these services, that speak our language, Punjabi, then it is easier to communicate with them. Some things you can’t communicate to White people, certain words don’t exist in English and it becomes much more difficult to explain, but with our own people who speak the same language, then they can understand, they understand our culture, the way we live, then it becomes easier for us. If there are more of our own people working in these services that would be something good (Participant SK-18, Male, First Generation, 42).

This not only benefited first generation participants but also younger bi-lingual participants who felt that having members of their own community delivering health services would allow older participants to be much more open within consultations and prevent the need for an interpreter. First generation participants preferred to have services delivered by members of their own community, who were considered to be individuals from the Sikh community, someone who not only shares a common language but can empathise with the practices and beliefs of the patient:

he (father) spoke to a Sikh lady... he was really happy that he got to speak with someone that could speak fluently, Punjabi and maybe understand the way he was feeling as well, understand their feelings but also understand their culture (Participant SK-07, Male, Second Generation, 22).

Hence, participants' views towards health professionals were based on their understanding of clear communication and preference for ethnic concordance with health professionals, which resulted in a greater contextual understanding of a patient's chronic condition.

8.5.1.2 Alternative sources of care and folk medicine for symptom management

The use of alternative sources and folk medicine is closely interpreted by participants' understanding of health professionals and disease management. As participants place considerable trust in health professionals they do not feel a need to extensively develop their own skills with regards to self-managing symptoms. Second and third generation participants who accessed the internet, for health related purposes, felt the GP was a convenient resource where they felt less knowledgeable with regard to searching the internet:

well not having a broad medical knowledge myself I wouldn't know what to search for on the internet and having the GP there on call is a better option than wasting time on the internet (Participant SK-05, Male, Second Generation, 18).

Therefore, there was greater dependency on the health advice provided by GPs. Participants may access health professionals for symptom management because they feel unable to use the internet appropriately to obtain health information, placing greater demand on the health professional system of support. This suggests the alternative sources and folk system is undeveloped with regards to symptom management.

Although participants questioned the legitimacy of resources accessed via the alternative sources and folk medicine system, it remained a system that was readily accessible. First

generation participants continued to have access to remedies from the subcontinent, either in the UK or India, while second and third generation participants had immediate access to the internet for health related information. As a result, participants valued the range of sources available:

I'm a member of the Diabetic Association now so there's always useful information that comes through and they've got their stuff online, but rather than being restricted to one it's always useful to look at lots of different things, see what else is around (Participant SK-09, Male, Second Generation, 51).

The internet was a valuable resource to gain knowledge about conditions and treatment, but participants remained cautious over self-diagnosis which remained the domain of medical health professionals. Participants continued to place greater value on medical knowledge disseminated and legitimised by health professionals and placed less value on knowledge provided by alternative sources.

8.5.1.3 Community and identity group membership for lifestyle management

The level of expectation to conform to established cultural values and practices was expressed by the cultural obligation of being hospitable towards guests. Hospitality was understood in relation to the term *Seva*: the provision of a selfless service with an underlying principle of altruism. *Seva* was understood in relation to a) the manner in which an individual addressed their guest and b) the provision of food and beverages which the individual perceives their guest would prefer to eat or drink.

Participants felt culturally constrained to present unhealthy food, such as fried foods, that prevented them from maintaining a healthy diet. Any change in established practices would be interpreted as disrespectful by their guests:

it's conformity isn't it, it's what other people would perceive to be good *seva* [selfless service] for them and you don't want to disrespect anyone that comes around, well that's what you're brought up with and it's something that you internalise and you don't challenge the *status quo* because the last thing, over any food or health, is you don't want people to walk away with a bad taste in their mouth, about the way you've treated them (Participant SK-02, Female, Third Generation, 24).

Therefore, the provision of food and drink is recognition by the host that the guest's presence is welcomed. Conversely, it remained difficult to reject unhealthy food/drink by guests who lived with chronic diseases. Guests felt obliged to accept food and drink while knowing it may be detrimental to the management of their diseases:

to someone else they think that you don't like their food, but I say I hope you don't mind I have these conditions and I can't eat these foods. Some understand others still say you have to eat something (Participant SK-10, Female, Second Generation, 45).

The practice of hospitality between guests and hosts acted as a substantial barrier to maintaining a healthily lifestyle and managing chronic conditions, as the need to conform to established traditions outweighed the importance of lifestyle management.

A number of people expressed a preference to exercise at home. South Asian communities, most notably Bangladeshi and Pakistani communities, have expressed a cultural stigma attached to exercising outdoors, particularly for women. The cultural stigma of exercising outdoors was also present in the Sikh community:

when my dad started jogging it was kind of looked down upon, he used to jog down Soho Road (Birmingham), and it's mainly an Asian community, and other people were asking my dad, 'how come you're running, is there something wrong?' (Participant SK-05, Male, Second Generation, 18).

The account highlights that the cultural stigma attached to exercising outdoors is also extended to males. None of the women recollected times of facing this particular cultural stigma, but rather expressed a greater preference for exercising outdoors:

I find it boring in the gym... and its better just being in the fresh air (Participant SK-06, Female, Second Generation, 42).

The community based network, and in particular membership to the Sikh community, allowed participants to develop their own personal self-management tools, in the form of spirituality and religious belief, to overcome emotional distress. Participants identified prayer as a suitable coping mechanism; alleviating distress and enabling individuals to cope with intense emotions, such as anger:

I recite my prayers and listen to my prayers, and with that the pressure you have in your mind, you never become angry, but that's what I think, I never become angry,

some people say even if you say your prayers you can still become angry, but I say if you pray, your anger, it will go far from you, it dies away (Participant SK-17, Female, First Generation, 70).

8.5.1.4 Family and support for emotional management

The constraining feature of the family system of support was how closed the network was towards external members. Emotional support was provided by a small number of people, notably married women to other married women. The risk of exposing emotional distress and maintaining confidentiality is a constraining mechanism within the family system; individuals over-utilised the same members in their kinship group:

If you tell someone else your household problems, then they make one problem into two or three problems, they make up many things, the issue might be quite small but when they tell someone else they will make it something big (Participant SK-10, Female, First Generation, 65).

As participants associated isolation with emotional distress, the need for family could be indicative that certain members of this community prefer to share emotional distress with close relatives. As a result, individuals used spirituality and prayer to deal with emotional distress, which is explored further in following section.

The family system of support was able to fulfil elements of care left unfilled in the health professional system. Participants felt family members, due to their background and already being part of their immediate network, would be able to understand the context of their

emotional distress such as issues with children and cultural obligations they were expected to fulfil; a shared understanding based on common causes of emotional distress:

there is always something happening in our families, like we worry about marrying our children or other problems like someone has just got divorced so there is always a problem (Participant SK-14, Male, First Generation, 51).

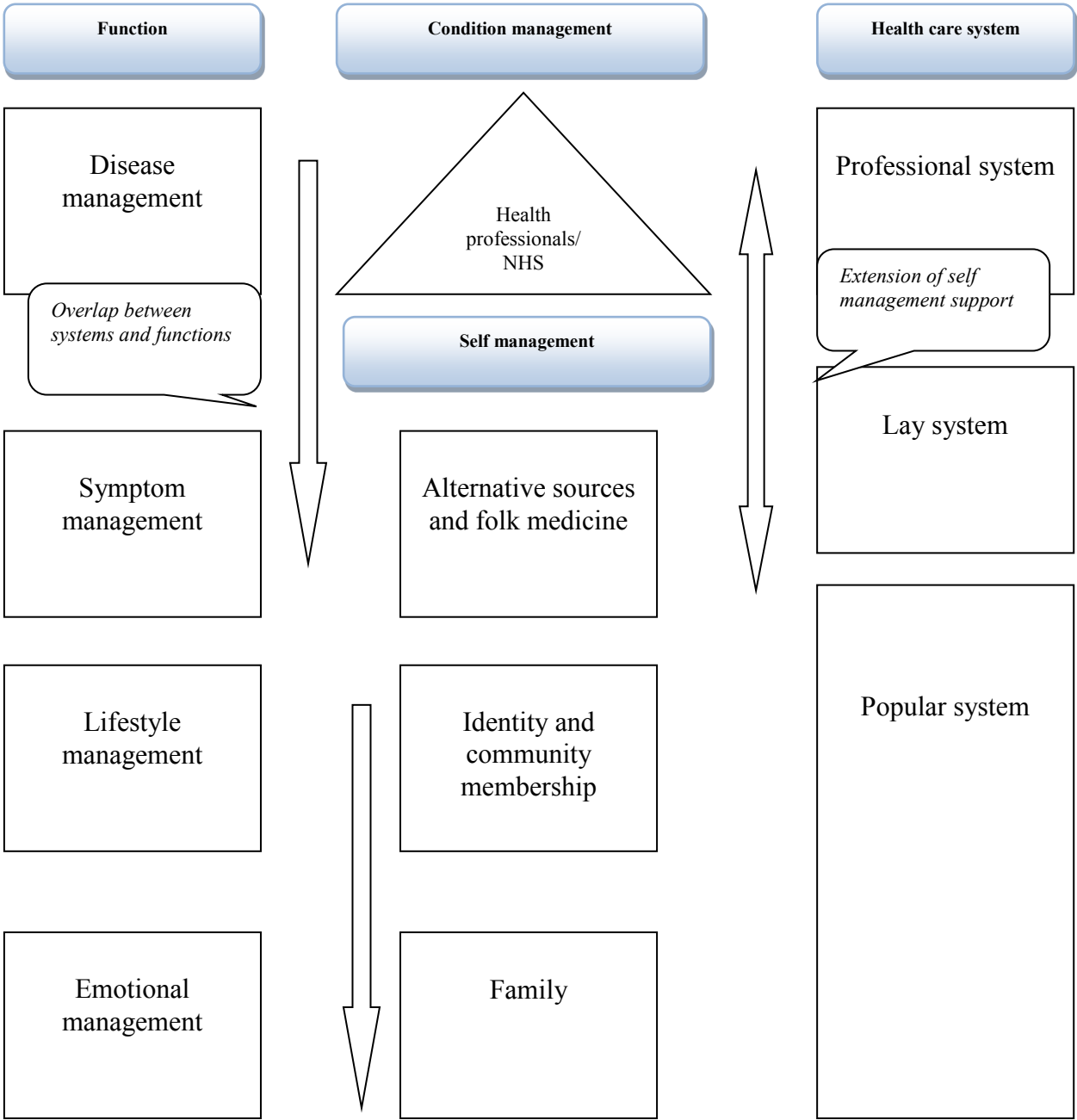
The affinity of a shared experience with members of immediate family led participants to believe that family members were suitable individuals to access for emotional support. Family members were most likely to have encountered similar experiences and therefore have a greater understanding of the impact socially and culturally interpreted events, such as divorce, could have with regards to emotional well-being.

8.6 DISCUSSION

8.6.1 Interpretation of findings

The system of support model provides a conceptual framework to understand the social context in which members of the Sikh community interpret chronic disease, management and well-being. The application of the framework demonstrates systems of support are determined by either dyadic relationships (one to one relationships with health professionals and family members based on trust and confidentiality) or ascribed membership to religious and caste communities (membership based on expectations or pressure to maintain cultural values and practices) (Vassilev *et al.*, 2010). Figure 16 provides an explanatory model explaining the role of self-management, chronic illness and systems of support within the Sikh community.

Figure 16: An explanatory model explaining the role of systems of support and self-management within the Sikh community



Analysis of findings show a community, rather than individual approach, should be taken to interpret self-management practices for individuals suffering from chronic diseases in the Sikh community. The systems of support associated with lifestyle and emotional management demonstrate close peers/family members have a considerable influence over behaviours that have both positive and negative outcomes.

Although systems of support have specific functions with regards to chronic disease management, the community, family and alternative systems are able to fulfil elements of support left unfulfilled by health professionals in relation to self-management. A distinct characteristic of all four networks is the limited number of individuals, where participants over utilised the same individuals for support. Evidence from existing literature (Roberto *et al.*, 2005; van Dam *et al.*, 2005) show networks (or systems) with a greater number of individuals are associated with better health outcomes, and networks that include family and friends are associated with better health outcomes compared to family only. As emotional management was provided by the family system of support, this could explain why participants expressed a greater number of symptoms associated with emotional distress compared to positive emotional well-being.

The social distance (how close individuals are to each other in each system e.g. immediate family, extended family) is as important as the geographical location where support is provided. Each system of support included (or participants expressed a desire to include) individuals who are South Asian, or more specifically, individuals from the Sikh community. This was particularly important to first generation participants who valued support from individuals who were perceived to share a common experience, similar life events and speak

in a single language. Male participants and their accounts of self-management support are underrepresented in findings. This may be due to less men being part of the sample and male participants being reluctant to talk about the emotional aspects of living with a chronic illness.

Participants expressed greater personal responsibility over lifestyle and disease management. The distribution of responsibility is dependent on relationships based on obligation. Support strategies and tools for self-management were reflective of the structure within systems. Systems which contained a limited number of actors, led participants to create strategies and mechanisms that could be readily accessed i.e. internet, or develop activities that could be completed in isolation such as prayer.

There was a significant difference in participants' accounts of the doctor-patient relationship between first generation, and second and third generation participants. Second and third generation participants demonstrated or expressed a consumerist position within consultations. A consumerist position does not involve a loss of authority or status on the part of the health professional, but a greater recognition by each party of their contributions (Lupton, 1996; 1997a; 1997b). The adoption of a consumerist position may be associated with the range of sources accessed by participants, where the availability of information allows patients to enter consultations with more informed questions. Although, as the majority of second and third generation participants were not living with chronic conditions, they have limited dependency on health professionals.

8.6.2 Cultural adaptation

8.6.2.1 Adaptation to content

Health services need to establish greater involvement with community and religious organisations with regards to lifestyle management, a core aspect of chronic disease self-management interventions. There needs to be a greater understanding of how cultural values and practices act as barriers and facilitators in changing health related behaviours, and how individuals can incorporate lifestyle behavioural changes while maintaining values and customs. Participants from South Asian communities attending CDSMPs should be provided with lifestyle information which can be incorporated with existing cultural values.

Using the internet as a tool for health-related information has been examined previously in the literature, with Hart *et al.* (2004) reporting similar findings to those presented in this chapter. Patients (majority White British), in Hart *et al.* (2004) study, had greater trust in their general practitioner and were not confident in their own ability to search the internet for trustworthy health advice. Therefore, further guidance or greater dissemination of how patients can find health information via the internet could benefit those living with chronic diseases.

8.6.2.2 Adaptation to delivery

With regards to health policy, first generation participants have a greater preference for receiving support from members of the Sikh or wider South Asian community, who they perceive as having linguistic and conceptual communication skills. Interventions designed for chronic disease self-management need to actively encourage immediate family members to attend with the person suffering from a chronic condition, as family members play a notable role in the care of close relatives.

There is a need for further research investigating the relationship between patients who share the same/different ethno-religious background with both lay and professional health care providers. The importance of pleasantries and conversational-informal talk has been investigated with African American populations but rarely with South Asian populations in the UK (Oliver *et al.*, 2001; Pauwels, 1990; Rawls, 2000). Older members of the Sikh community valued health care providers who used pleasantries. Organising interpreters was a significant barrier for first generation non-bi-lingual participants often asking family members to attend appointments. Conversely, the use of family members as interpreters is perceived inappropriate in health care settings (Chamba and Ahmed, 2000; Gerrish, 2001; Robinson 1998). Greater attention needs to be given to conceptual communication as the benefit of linguistic communication is often cited as the primary advantage of using health care providers from the community (Naqvi, 2003). Finally, greater attention needs to be given to extended families acting as care givers for people suffering from chronic conditions, as studies have shown that female members take on greater responsibility care compared to male members (Katbamna *et al.*, 2004).

8.6.3 Revisiting the literature: Originality of findings in this chapter

Exploration of health beliefs within the Sikh community has demonstrated that there are existing and complex systems of support that exist which go beyond professional healthcare. Participants held varying views with regards to folk medicine. Studies have found that South Asian individuals consider western medicine as more powerful than medication from the subcontinent (Nichter and Nichter, 1996). However, findings in this study demonstrated medication from the subcontinent is used in a supplementary manner for symptoms rather than as an alternative. Consequently, health professionals may need to explicitly ask whether

participants are taking any medication from the subcontinent rather than asking if they taking any other medication.

This is the first study which explores the influence of caste, religious and cultural values on self-management behaviours across three generations of the Sikh community in the UK. For instance, second and third generation women are more likely to consume meat and drink alcohol compared to their first generation counterparts but still likely to experience a similar cultural stigma.

The role of the ‘family’ in the Sikh community differs from other communities. Rosland *et al.* (2010) reported spouses played some role in self-management once patients were diagnosed with chronic diseases. Conversely, this research within the Sikh community showed children made a greater contribution when helping parents or grandparents; attending consultations, interpreting and translating, and ordering prescriptions. The absence of spousal support may be one possible reason why married women accessed emotional support from other married women in the family network. These findings may also be applicable to other South Asian communities. For example, the lack of male spousal support has been cited in studies with Muslim women experiencing the symptoms of depression who then require social treatment (Gater *et al.*, 2009)

8.7 SUMMARY

The findings in this chapter attempt to build on existing interpretations of chronic disease and self-management and apply them to a specific ethnic group. Health professionals continue to be the most valued system of support with regards to disease management. However, alternative sources, community and identity groups (i.e. people of *Jatt* caste or Sikh faith), and the family provide specific and cross cutting support within the broad spectrum of everyday self-management. The functions, and subsequent enabling and constraining properties, are inter-dependent i.e. functions were dependent on what certain systems were able to fulfil and unable to fulfil. There were a limited number of relationships that existed within each system, with interactions heavily based on one-to-one interactions and the absence of third parties. The responsibility of the long-term management of chronic illnesses and/or general well-being was placed with the individual, health professionals and close relatives that were part of the family system.

Systems of support that related to everyday self-management played a greater role in areas of self-care traditionally associated with individual patient responsibility. A social approach to understanding chronic disease and self-management demonstrates that obligation and attachment to values, customs and traditions in systems of support have a significant influence on behaviour. Finally, although participants cited a limited number of individuals within each system they did not state a desire to access resources from a greater number of lay, non-professional or professional individuals. In the next chapter I provide a conclusion to my research citing the key findings, recommendations for policy and summarise areas for further research.

CHAPTER 9

9.0 CONCLUSION

9.1 INTRODUCTION

In this chapter I summarise the key findings from the evaluation of the Chronic Disease Educator (CDE) programme and inductive exploration of health beliefs in the Sikh community. The methodological considerations of my studies are presented, with particular emphasis on assessing whether a robust theory-based evaluation of the CDE programme was carried out and how findings are transferable to other research settings/populations. I continue by illustrating the contribution[s] made by my research and how it relates to and supports existing literature. The implications for practice and policy section addresses how my research could influence health service provision (in the future) for people living with chronic diseases. This section also describes how the evaluation of the CDE programme has already influenced the delivery of self-management services across the city of Birmingham. I conclude the chapter by providing suggestions for further research, highlighting the limitations of my findings and provide some personal reflections. I begin the chapter by demonstrating how the aims of my study have been achieved. The involvement of colleagues in this study is described in Appendix 13.

9.2 SUMMARY OF THESIS

9.2.1 Phase 1: Theory-based evaluation of the Chronic Disease Educators programme

The aim of Phase 1 was:

To conduct a theory-based evaluation of a lay-led, group-based chronic disease self-management intervention

I achieved this aim as follows. Firstly, the inclusion of self-assessment participant data (pre and post intervention) showed self-management interventions can have a positive effect upon individual health status (cognitive and clinical); however, improvements were statistically significant but not clinically significant and may not be maintained in the medium to long term. Attendance and completion rates indicate a high level of acceptability of the programme by participants; nevertheless, completion rates from South Asian communities were amongst the lowest. A possible solution could be the inclusion of an additional session or ‘workshop zero’: a workshop held before an intervention formally begins to provide information about the programme, collect baseline data, and give participants the opportunity to bring their own suggestions on what information they would like.

Secondly, I interviewed all six CDEs that were, at the time of data collection, delivering the intervention. The intention was to understand CDEs’ attitudes towards delivering the intervention to socio-economically disadvantaged communities. Their accounts demonstrated the cross-cultural experience of teaching ethnically-diverse communities about healthy living and self-management, detailing the intricacy involved when dealing with health beliefs and providing medically informed health information. CDEs spoke about their perceptions of the needs of the local community and how they attempted to alter the content and style of delivery to, predominantly, accommodate people from South Asian communities. CDE experiences of delivering the programme led to the recognition of their own perceived training needs. Training related to one predominant area, programme delivery. This was further broken down in two specific areas for development; acquiring appropriate ‘teaching skills’ for adult learners and establishing a better working relationship with interpreters. However, lay educators also identified their strengths, as all CDEs felt they had enough

culturally competent knowledge of health-related attitudes and practices prevalent in minority-ethnic groups.

Thirdly, observation was carried out to develop a greater understanding of how self-management interventions are implemented. This was achieved by observing CDEs delivering the programme (with interpreters and in community languages) to different ethnic, gender and age groups living with various chronic conditions. Observation revealed varying levels of knowledge with regard to content provided. South Asian individuals showed lower baseline knowledge and were perceived to benefit more from the cultural adaptations used in the programme compared to other ethnic groups.

Most notably, members of the South Asian community appreciated visual aids, although CDEs questioned the cultural relevance of some materials. As a result, greater culturally appropriate visual aids for poorly educated, non-literate communities are required to successfully deliver self-management interventions for members of minority-ethnic populations. A set of requirements also need to be established in terms of delivering health interventions in community languages. A number of studies, conducted with minority-ethnic groups have expressed the need to deliver health services in community languages (Bhopal *et al.*, 1988; Gerrish *et al.*, 2004; Hawthorne *et al.*, 1994), and findings in this study have identified particular requirements for health education programmes. Interpreters can potentially build a 'link' between lay people and participants from the community but the parameters of their role beyond translation should be defined prior to delivery. Ideally, interventions designed for minority-ethnic groups should be delivered in a single community

language. The presence of multiple languages leads to the possibility of miscommunication and isolation for the participant.

As discussed in Chapter 7, lay people delivering self-management interventions need to be trained to apply behaviour change techniques. CDEs were competent at informing participants about healthier practices but behavioural changes were often the result of personal endeavour by participants rather than encouragement from the CDE.

Finally, participant interviews were conducted with people of different ages, gender, and ethnicity, providing contextualised accounts of living with and self-managing chronic diseases. Accounts highlighted that all participants were self-managing (with some citing a number of behaviour changes) before they had attended the CDE programme. Again, members of South Asian communities welcomed cultural adaptations: delivery in community languages, culturally relevant content and use of visual aids. Within a short period of time participants developed close relationships with CDEs, supporting aspects of self-management left unfilled by their GP. Participants gained a number of things from the programme ranging from knowledge acquisition to sharing narratives, but this was largely dependent on how well a person was self-managing prior to attending the programme. Importantly, participants' accounts of living with chronic conditions were socially contextualised, often discussing wider social factors acting as barriers to healthy living.

Collectively, these findings provide evidence that there is a need for chronic disease self-management programmes and they are considered an acceptable method of service provision by people from socio-economically disadvantaged and minority-ethnic groups. Conversely,

this does raise the question whether self-management interventions should be culturally tailored for specific ethnic-minority groups. Given the perceived appreciation of cultural modifications to delivery and content, self-management interventions which incorporate the majority (if not all) of cultural adaptations listed in the taxonomy presented in Chapter 3, would be better designed for members of the South Asian community born outside of the UK.

9.2.2 Phase 2: Exploration of health beliefs with the Sikh community

The aim of Phase 2 was:

To develop a greater understanding towards chronic disease and self-management with a population that is at risk of developing chronic conditions.

This aim was achieved as follows. This phase of the study is the first time health beliefs, specifically about chronic disease and self-management, have been explored across three generations in the Sikh community in the UK. Furthermore, it is the first time Rogers *et al.* (2011) systems of support framework have been used to interpret participant accounts regarding chronic disease self-management.

The findings generated from interviews with members of the Sikh community support the Whole System Informing Self-management Engagement (WISE) approach developed by Kennedy *et al.* (2010). The aim of the WISE was to develop an appropriate self-care support for people with long-term conditions. A key objective of WISE is practitioners being trained to be more supportive of patients' needs and build on the patient's existing skills. An important feature of the WISE approach, for members of the Sikh community, is primary care

teams having a ‘menu of options’ (Kennedy *et al.*, 2010); practices having a list of local resources/options available to provide self-care support such as web-based information resources, group support e.g. EPP courses or information about patient support groups. Analysis of findings showed members of the Sikh community interpreted their GP as the first port of call for any health concern; therefore, it would be the most appropriate location to provide patients with information about other services which could support self-management of chronic diseases.

Communication remained a key factor for members of the Sikh community, represented by the need to have members of their own community (or wider South Asian community) within each system of support. This highlights the importance of linguistic and conceptual communication between participants and health care providers. However, a key finding was that the lack of support available for self-management influenced the type of mechanism participants chose to manage chronic diseases. Finally, analysis identified four areas of chronic disease management; disease, lifestyle, symptom and emotional management, providing a clearer understanding where facilitators and barriers to healthy living exist.

9.3 METHODOLOGICAL CONSIDERATIONS

Firstly, I will go through each of White’s (2009) six principles of using a theory-based evaluation to demonstrate the level of creditability of my findings:

1. **Map out causal chain (programme theory)**- the origins of the design of the programme have been detailed and the intervention has been described using a self-developed reporting criteria for interventions (Chapter 5, Pg. 154)

2. **Understand context**- findings have been interpreted with a particular emphasis on understanding the cultural and social context in which the management of long term conditions occur e.g. impact of state legislation, loss of employment, perceptions of self, religious and cultural values (Chapter 6, pg. 179; Chapter 7, pg. 208; Chapter 8, pg. 252)
3. **Anticipate heterogeneity**- data were collected from a range of respondents/research settings accounting for ethnicity, age, gender, chronic condition and language (Chapter 4, pg. 113)
4. **Rigorous evaluation of impact using a credible counterfactual**- the stages of data analysis have been meticulously reported and deviant cases have been included where available in the presentation of findings (Chapter 6, pg. 179; Chapter 7, pg. 208; Chapter 8, pg. 252)
5. **Rigorous factual analysis**- a rich, detailed and descriptive analysis and interpretation has been conducted demonstrating the impact of programme components with members from various ethnic groups (Chapter 6, pg. 179; Chapter 7, pg. 208; Chapter 8, pg. 252)
6. **Use mixed methods**- a range of methods have used to collect data from both quantitative and qualitative methodologies (Chapter 4, pg. 113)

The evaluative and exploratory nature of my study, which included participants with language and literacy concerns, meant this study required a predominantly qualitative approach. The nature of my research questions, which endeavoured to gain a greater understanding of chronic disease and self-management, also influenced the type of data collection method

chosen, such as using semi-structured interviews with a narrative based approach with participants living with chronic diseases.

As someone who resides in Birmingham and a member of the South Asian community (specifically the Sikh population), this placed me in a privileged position and provided the opportunity to give an insider perspective (Ergun and Erdemir, 2010). My insider perspective led to a nuanced analysis in relation to the social and cultural context surrounding participant accounts (Ong and Richardson, 2006), particularly evident with analysis of data from the Sikh community (understanding the role of cultural values upon self-management behaviours). Having a shared background with participants helped to overcome linguistic difficulties and conceptual misunderstandings of cultural practices. Participant linguistic skills amongst older members of the South Asian community were poor. Many found it difficult to articulate emotions, especially how their illness influenced social aspects of their lives and their general emotional well-being. Also, this was probably the first time they had been asked questions about their illness, health beliefs and aspects self-management, as the recruitment of minority-ethnic groups in research is generally low (Hussain-Gambles, 2003). This may partly explain why certain people used psychosomatic presentation within their accounts.

The greatest advantage of having a shared identity with participants was the absence of interpreters (with the exception of one interview) which allowed me to build rapport with participants and ask questions directly without having to wait for translation. Furthermore, as I was the interviewer who transcribed, coded and analysed data, I was able convey an interpretation of data from collection to presentation in this thesis. As a result, I was analysing data which were all collected first hand. Transcripts were analysed once they were translated

from a community language into English. Due to time and cost constraints I was unable to have transcripts independently transcribed/translated. However, transcriptions were verified by a fellow South Asian doctoral researcher (listened to an audio recording alongside translated transcription) to ensure conceptual equivalence had been maintained (Hipwell, 2009).

In relation to rigour, a large volume of data was collected throughout both phases of the study (46 interviews, 14 observations and 1166 self-reported participant questionnaires) and from range of respondents; a large sample size for a predominantly qualitative study (Denzin and Lincoln, 2000). Furthermore, meetings were routinely held with local commissioners of health services and Health Exchange, feeding back interim reports and discussing potential changes to the service once the evaluation was complete. There were areas that may have improved rigour. The inclusion of descriptive data from participants who dropped out or declined the CDE programme would have been valuable, eliciting reasons for non-attendance. A greater number of interviews with third generation individuals of the Sikh community could have led to greater nuanced analysis, identifying differences in their views compared to second generation descendants.

The aim of this study was not to produce findings that were generalisable but transferrable to other research settings and populations (Mason, 1996). Findings from the theory-based evaluation are applicable to other chronic disease self-management interventions with regards to analysis of the group format, effectiveness of cultural adaptations and style of delivery within workshops. Findings from the Sikh community have relevance to barriers and facilitators to behavioural change which may exist in other South Asian communities residing

in the UK, and provides the potential for theory building. Reliability was ensured via inter-researcher coding and holding meetings with academic supervisors to discuss the generation of themes. The inclusion of interview guides and examples of codes/analytical memos with this thesis allows the reader to determine the accuracy of my analysis.

Similar to previous studies, the problem of recruiting members from minority-ethnic groups, whether they are illiterate and/or born outside of the UK, remains. Bhutta (2004) states illiteracy does not necessarily mean participants are unable to comprehend complex information. Consequently, efforts were made to include illiterate members of the community and present information about the study verbally as well as in written form. Although recruitment was difficult, qualitative methods are suitable for data gathering with poorly educated individuals, as often people may have difficulty completing questionnaires without assistance (Lloyd, 2007). Unsurprisingly, the role of gatekeepers remains important to generate sizable samples and build trust with participants, even when researchers share a common background (Ely, 1991). Participants living with chronic diseases were referred by CDEs and the Health Exchange, therefore there is potential bias as participants who would give a preferable opinion about the CDE programme may have been selected.

Within health research, ethnicity has become widely recognised as a concept which is self-perceived and subject to change over a period of time (Heath, 1991). Members of my study were asked to provide their ethnic and/or their religious status but participants of Indian, Pakistani and Bangladeshi heritage members were often grouped under 'South Asian' for ease of analysis. Evidently, when I refer to South Asian participants, I have grouped together people who practice different faiths, cultures and beliefs. In addition, qualitative studies

carried out with South Asian participants are often geographically representative (Choudhury *et al.*, 2008; Rankin, 2001; Stone, 2005) i.e. studies conducted in the West Midlands are more likely to include Indian/Sikh/Hindu participants, in London (especially east London) they are likely to include Bangladeshi/Muslim participants, and in the North of England they are likely to include Pakistani/Muslim participants (SAHF and Diabetes UK, 2009).

All of these groups would have different experiences of self-management as their social and economic areas differ, affecting access to resources, level of income and availability of suitable employment. Nevertheless, through my analysis of participant accounts from the CDE evaluation I was able to detect differences in attitudes by religion, which led to exploration with the Sikh community, rather than the Indian community. In order to improve research with minority-ethnic groups, researchers firstly need to recognise the difficulty in categorising groups together for analysis and play greater attention to differences, declaring why certain terms have been used and how they have been interpreted (Senior and Bhopal, 1994).

Given the long term settlement of minority-ethnic groups in the UK, which has led to second and third generation descendants, researchers should place greater attention to levels of acculturation. As demonstrated in Chapter 8 many of the younger participants practiced values, beliefs and lifestyles associated with British culture which ultimately influenced their perceptions of health and well-being. Hence, greater importance should be placed on measuring levels of acculturation as only a limited number of studies have focused on this (Wyke and Landman, 1997) and have generally paid greater attention to health beliefs. According to Phinney (1992) it would also be valuable to measure certain aspects of

acculturation such as social networks; this is important especially given the context of Rogers *et al.* (2011) work and subsequently my research. As a result, health professionals need to develop a greater understanding of social networks and values adhered by second and third generation minority-ethnic people.

9.4 THEORETICAL LITERATURE

9.4.1 The work of Paulo Freire

Although not used as an explicit framework, the body of work developed by Paulo Freire informed interpretation and critical perspective. The identification of Freire's (1970) key concepts influenced interpretation of findings from the CDE programme in the following way:

Praxis: The intention was to examine whether participants were able to critically reflect upon their social reality. Participants concentrated on the financial aspects of their reality such as grocery shopping with a low income and/or the inability to find or maintain employment. Only some lay educators attempted to engage in conversations with participants about their social reality. Lay educators were able to acknowledge the social reality participants faced but did little to support action to improve it. Participants and lay educators, whilst attending CDSMPs, need to engage into conversations about the wider social environment (Nutbeam, 2000) to encourage patients to adopt healthier behaviours.

Dialogue: This concept led to a close consideration of the relationship between lay educators and participants; whether a relationship based on equality, respect and trust was established (Freire, 1970). Participants were able to build trustworthy relationships and due to a shared

language and culture South Asian participants were able to have a more participatory role. Nevertheless, South Asian participants were much more respectful to CDEs and saw them as dominant figures directing the workshop. This led South Asian participants to be much more receptive rather than critical. Wallerstein and Sanchez-Merki (1994) argue critical thinking does not happen spontaneously but has to be promoted during dialogue. Giving people the opportunity to narrate personal stories can lead to critical discussions about the consequences of risky behaviours and subsequent solutions (Wallerstein and Sanchez-Merki, 1994)

Banking: This concept was explored under the theme delivery and learning styles. In the majority, health information was passed from a knowledgeable lay educator to poorly informed participants. Although many of the participants accepted they were not knowledgeable enough to provide peers information, some did question whether the information the CDE was providing would be helpful to better self-manage their chronic diseases. Hence, information was ‘banked’ by participants but they need a personalised response with regards to why they should place information into action.

Conscientization: Freire (1972) states conscious raising requires cultural formation. For South Asian participants, cultural values and beliefs played a prominent role in the behaviours they practiced. Lay educators demonstrated significant difficulty challenging established health beliefs and informing participants that certain practices acted as barriers to managing their chronic diseases. This may be unsurprisingly because culture is often synonymous with identity for first generation migrants (Clarke, Pearch and Vertovec, 1990). Therefore,

participants may acknowledge areas that influence their social situation but this does not mean they are ready to act and make changes (Aronowitz, 1993).

9.4.2 The work of Michael Foucault

Foucault's body of work (1975) was used to inform the interpretation of participant's accounts, understanding notions of responsibility and being healthy. The themes 'living with chronic conditions' and 'incorporating new skills' demonstrated the level of individual self-surveillance practiced by participants and responsibility when making behavioural changes. However, self-surveillance and practicing control meant participants' interpreted the process of making and sustaining behaviour change negatively. The responsibility participants felt to make behavioural changes was closely linked to perceptions of self; participants wished to remain independent while living with chronic diseases and maintain many of the characteristics they held prior to diagnosis.

The relationship between power, knowledge and the body (Foucault, 1975) was prominent throughout the research. Firstly, as participants became more knowledgeable they were able to make better informed decisions with regards to implementing behaviour changes in their lifestyle. Secondly, for members of the Sikh community, power was represented through the relationships people had with systems of support. For instance, membership to community and identity groups played a significant role in the type of behaviour a person practiced in particular social contexts. Hence, individuals were subject to power relations which influenced their ability to make informed decisions about their behaviour.

Rose (1999) coined the term '*Healthism*' to describe that the responsibility of being healthy had moved from the state to the individual. Many of the interviewees who attended the CDE programme felt responsible for trying to remain as healthy as possible given their chronic diseases. Women showed a willingness to remain slim while men recalled positive experiences of employment. Therefore, unconsciously many of the beliefs participants spoke of were aligned with public health objectives of the UK government. However, such beliefs may have been more prominent as interviews were conducted after participants had attended the CDE programme; an intervention providing health education which reinforces public health policy (Gastaldo, 1997).

Younger interviewees from the Sikh community represented many of the consumerist attitudes presented by Lupton (1995; 1997) building on Foucault's work. Conversely, rather than 'shopping around' for services that best fit their health needs members of the Sikh community, regardless of age, would primarily visit their GP for health concerns. The trust and faith members of this community had with their GP was difficult to replicate with other professional or non-professional health care providers. As a result, this has implications for GPs and the style of consultation they have with patients from the Sikh community. Firstly, GPs should acknowledge not all patients may wish to be part of the decision making process but may want to be kept informed of decisions. Secondly, during consultations, GPs should be able to inform patients about other reliable sources of health information e.g. websites, which may answer their queries and lead to a reduction in using primary care services. Finally, GPs should acknowledge that religious and cultural values play different roles in the lifestyles of many Sikh people and should not provide treatment based on traditional culturally-assumed premises.

9.5 IMPLICATIONS FOR PRACTICE AND POLICY

This study has shown chronic disease self-management programmes, with cultural adaptations, can help people better manage their chronic conditions. Interventions which are culturally competent, with regards to content and delivery, are particularly suited for members of the South Asian community born outside of the UK. Nevertheless, the cultural adaptations used in the CDE did not always achieve positive outcomes and had some notable drawbacks. A critique of the cultural adaptations used in the CDE programme (and applicable to other health education interventions) is presented in Table 25.

Table 25. A critique of cultural adaptations used in the CDE programme

Components of programme	Summary of component	Intention	Possible drawback
Delivery in various community languages and use of interpreters	Many of the lay educators recruited from the community are able to converse in a number of South Asian languages i.e. Urdu, Sylheti, Punjabi Grouping of participants with language requirements	Clarity in translation Participants are able to ask questions immediately Participants are likely to have similar learning requirements are perhaps find it easier to relate with other members of the group	Disrupting for participants who can speak English Stop-start feature to the session Chain of translation which leads to loss of content Time consuming CDEs having to work around terminology Use of interpreter means CDE could become isolated from the group
Cultural adaptation of educational material	Adapting the content of the programme for South Asian participants- use of Asian brands, cooking methods	Makes content much more applicable to South Asian participants Much more of a personalised/ culturally based approach	Content may need greater explanation for non-Asian participants or perhaps would not be relevant e.g. cooking methods
Group activities	A number of activities played out within the group: 'Eat-well' Plate- placing food cards into relevant food groups Sugar and oil content in commonly eaten foods Taking BMI and blood pressure readings Guided imagery Freethink	Participants interacting with each other- peer identification and peer-to-peer learning Greater engagement with content Participants have the opportunity to ask questions throughout activities	Interaction across the group often depends on the number of people in the group- 6-8 people considered to be ideal Some group members may become isolated Certain members may be more vocal than others

The use and application of visual aids	<p>The use of various visual aids within group activities:</p> <ul style="list-style-type: none"> Test tubes of sugar and oil Fat belts Food cards Diagrams of the heart and arteries Visual diagrams of cultural foods e.g. East End lentils 	<p>Appears to make content easily understandable for participants (as majority are likely to have low literacy levels)</p> <p>Intended to make a clear take home message i.e. that certain foods/ practices are detrimental to health while others are better</p>	Content may appear to be too basic for some participants who already have some prior knowledge of the content
Action planning	<p>CDE programme outlines that at the end of each session participants (with the aid of the CDE) should set realistic goals based on content they have just covered</p> <p>These goals should also be achievable in a relatively short space of time</p> <p>These goals are then reviewed at the beginning of the next session via a 'group round up'</p> <p>The use of exercise and food diaries are encouraged to help participants reach their goals</p>	<p>Encourages participants to implement content into their lifestyles</p> <p>CDE can answer questions participants have with regards to reaching their goals</p> <p>Diaries allow participants to write down and review changes they have made over time</p> <p>Diaries can also identify where behavioural changes can be made</p>	<p>Goals need to be reviewed the following week to discuss any issues the participant has faced, otherwise participant may become de-motivated</p> <p>Goals need to be specific and not vague i.e. lose weight</p> <p>Diaries should be reviewed with the help of the CDE as participants may not have the skills or knowledge to identify where changes can be made</p> <p>There was no use of exercise diaries and food diaries were not reviewed by the CDE the following week</p>
Emotional well-being	<p>A key area of the programme is helping participants with emotional concerns they have encountered</p> <p>CDEs use a number of relaxation techniques such as guided imagery, prayer, 'breaking vicious cycles' and breathing exercises</p>	<p>Participants feel as if an emotional 'weight' has been lifted as they feel they have someone who listens to their concerns</p> <p>Participants enjoyed narrating their experiences of living with chronic conditions and felt better when listening to the experiences of others</p>	<p>Participant narratives can be very time consuming (especially in a larger group)</p> <p>Discussions can become very personal and tackle sensitive issues</p> <p>Some people may not feel comfortable talking in a large group</p>

Educational delivery and content	<p>Programme is centred on providing participants information on chronic conditions (with diabetes mellitus, CHD, CKD); symptom management, healthy behaviours (diet and exercise) and managing the emotional impact of their illness</p> <p>There are a number of different styles used to deliver the content: didactic, facilitative and the use of group activities</p>	<p>Participants with a perceived lower baseline knowledge of the content appeared to learn much about their illness and symptoms</p> <p>South Asian participants enjoyed the didactic approach</p> <p>Content gives importance to non-medical aspects of living with a chronic illness</p>	<p>Lack of personalisation to the specific needs of the participant</p> <p>Lack of testing to see whether participants have understood content</p> <p>CDE can spend vast amounts of time tackling folk beliefs</p> <p>Certain topics of discussion may be avoided as they could be perceived as being too 'medical' i.e. medication adherence</p>
Implementing healthier behaviours	<p>A number of activities incorporate problem solving such as tackling barriers to healthy eating and daily exercise</p>	<p>Discussions on perceived barriers and benefits of making healthier behavioural changes appears to make participants at least think about making changes</p> <p>Self-efficacy- group discussions allow participants to assess their own ability to successfully adopt healthier behaviours</p>	<p>There is a need to discuss social conditions that may hinder one's ability to make healthier behavioural changes</p> <p>Time should also be spent on how changes can be made and implemented in participant lifestyles</p> <p>Making healthier behavioural changes may need to be incentivised to motivate participants</p>

A number of considerations should be made in relation to the implementation of health services for people living with chronic diseases and self-management interventions designed for people from economically disadvantaged and/or minority-ethnic groups. A greater number of methods which encourage peer-to-peer discussions should be used. These discussions should be based on participant experiences of positive self-management practices and how behavioural changes can be maintained i.e. identification of type of behavioural change, benefits of making a change, implementation and sustainability. Hence, behavioural changes need to be interpreted as positive experiences and not understood in terms of control and restraint. This could be achieved by pairing newly diagnosed participants with those who have lived with a chronic condition for a number of years.

Lay people delivering interventions to people from minority-ethnic groups should actively counter health beliefs which are used to justify unhealthy practices. Yet, lay people need to be aware health beliefs are often well established and culturally ingrained; therefore, cultural sensitivity is a necessity. The recruitment of lay people from the community had greatest benefits for members of the South Asian population, demonstrating strong communication skills and cultural knowledge about health practices and behaviours. Although members from non-South Asian groups developed close relationships with lay educators, participants cited few other benefits. Nevertheless, lay educators are able to demonstrate a wide range of skills and remain a relatively low cost approach (compared to health professionals) of delivering self-management interventions.

Lay educators need to instigate more conversations regarding social structural factors, such as low income, access to health services, or loss of employment. Such conversations could help

patients learn from each other about ways of overcoming structural barriers or instigate a social movement group, campaigning for changes to be made within the community.

Engaging in community-based action and critically engaging in conversations about the wider environment corresponds with Freire's (1970) beliefs regarding education for disadvantaged communities.

Carr and colleagues (2011) recently completed an evidence synthesis of the effectiveness and cost-effectiveness of health-related lifestyle advisor roles in improving health. Their results show the aim of lifestyle advisors (lay people) is not to encourage behaviour change but to help people live with a chronic disease and found promising signs that 'buddy schemes' (pairing participants with similar experiences together) can be beneficial. Overall, results from the synthesis showed lifestyle advisors had a positive impact on participants' health knowledge, behaviours and outcomes. However, they concluded that there remains ambiguity in respect to the role and called for greater attention to be given to lifestyle advisor-identified training needs.

Finally, lay people recruited from the community should be assessed for their suitability to deliver services to minority-ethnic groups. For example, individuals should be assessed on their ability to communicate in community languages, whether they have previously worked with ethnic minorities and any previous roles or training undertaken which may help them to deliver health interventions. Furthermore, lay people should be evaluated in relation to cultural competency using criteria developed by Papadoplous (2006), which covers four areas: cultural awareness, cultural sensitivity, cultural knowledge, and cultural competence.

An important area in the development of self-management interventions is to test whether participants have understood the content provided on the programme. Testing identifies what participants have learnt (or not learnt) from the programme, which may indicate the likelihood of participants making behavioural changes. Introducing a 'workshop zero' would provide the opportunity to test participants' baseline knowledge which could then mean participants attended an intervention which is best suited to their needs.

The CDE programme experienced substantial attrition from the end of the programme to three month follow-up. This indicates the need for interventions to maintain greater contact with participants once the final workshop has been completed or embedded in general practices. Self-management interventions delivered in the US and the UK have used telephone-monitoring (Lorig *et al.*, 2005; McManus *et al.*, 2010), arranging telephone conversations with participants to discuss the process of incorporating healthier lifestyle choices and providing motivational support. However, self-management interventions delivered with telephone support have shown inconclusive clinical results for people living with chronic diseases, but are well accepted by patients (Pare *et al.*, 2007).

Overall, the effectiveness of self-management interventions for minority-ethnic groups can only be determined with longer term follow-ups. The quantitative findings were only substantially measured at the end of the intervention; hence, generalisations from quantitative outcomes are limited as changes in clinical and cognitive outcomes were measured after three weeks. Therefore, data needs to be collected over a greater length of time (end of intervention, 3 months, 6 months and 12 months follow-up intervals) to determine long term effectiveness. Within a UK context, the collection of clinical data (systolic and diastolic blood pressure

measurements, BMI) may be done in conjunction with primary care. The cultural adaptation taxonomy (Chapter 3) should be used as a tool to assess whether interventions and health services are appropriately designed to meet the cultural needs of its participants. Its development and application with the CDE programme shows that is valuable instrument and helps to determine the value of adaptations with various ethnic groups.

Inductive exploration with the Sikh community shows that a greater detailed understanding of self-management is required beginning with the four different systems of support presented in Chapter 8. Although the NHS provides the majority of support for disease management there remain areas of self-management which primary care services are unable to fulfil. As a result, the contribution of the lay health care sector needs greater evaluation with regards to its role in chronic disease and self-management. The type of self-management support provided is also influenced by location and meanings attached to place. Therefore, this raises questions about the suitability of religious locations as places to deliver health services, as they may fulfil practical requirements (access to target group, large space, easy to access) (Coe and Boardman, 2009), but places of worship are bound by values and doctrine and they may act as potential barriers to self-management. Lastly, cultural values were identified as playing a significant role in influencing health-related behaviour, specifically acting as a barrier to lifestyle management. Health services designed to deal with chronic disease and self-management need to demonstrate how healthier behavioural changes can be made while cultural values can be maintained.

The NICE guidelines (Bury *et al.*, 2005) reviewed in Chapter 2 on lay-led chronic disease self-management reported the emergence of CDSMPs was as much a product to reduce the

cost of managing chronic conditions as well as reflection of current political thought. In particular, the development of CDSMPs fits well with the political rhetoric of a ‘patient-led’ approach, although, analysis of findings has shown self-management is dependent on factors beyond the self. Therefore, interventions should continue to provide additional information on local services which may be of benefit to participants, such as low cost membership schemes to local council run services and access to welfare resources.

9.6 CONTRIBUTION TO EXISTING LITERATURE

This is the first time an evaluation of a chronic disease self-management programme with White and BME groups delivered in Birmingham has been conducted. This is also the first time health beliefs about chronic disease and self-management have been explored across three generations of the Sikh community in the UK.

Many of the findings identified within the Sikh community may also be applicable for other South Asian communities such as Muslim Pakistani and Bangladeshi, and Hindu Gujarati’s. For example, the extended family structure present in the Sikh community is also common in other South Asian communities; hence, family members in these respective populations may also play some role in self-management for chronic disease sufferers. In addition, community values influencing behaviour may also be applicable to other South Asian communities, particularly the role play between hosts and guest when presenting food/drink. Analysis of findings also identified that second and third generation men and women held health professionals e.g. GPs, in high esteem, similar to first generation migrants.

Another contribution is the broader contextualisation of health needs, with regards to self-management, for members of the Sikh community. Findings from the Sikh community show that CDSMP programmes are not suitably designed to cover all aspects of self-management practised by people in this community. More importance should be placed on dealing with emotions, alternative/traditional/indigenous remedies and the role of faith in managing chronic diseases.

Chapter 8 is the first time self-management has been explored in four specific domains: disease, symptom, lifestyle and emotional management. While these areas overlap at times, analysis reported how these different areas acted as barriers and facilitators for people living with chronic diseases. Hence, interpretation of findings has gone further than broad definitions of self-management and disease management and into areas that are embedded in the Sikh community and may be applicable to other South Asian communities living in the UK.

9.6.1 Implications of original findings

The findings presented in this thesis have many implications for people delivering health services to patients living with chronic diseases.

Firstly, findings presented in this thesis support the argument that CDSMPs should be culturally adapted for members from South Asian communities, particularly for first generation migrants. A recent review by Marshall, Wolfe and McKeivitt (2012) of qualitative research investigating lay perspectives on hypertension and drug adherence, found that many studies recommended culturally appropriate education. However, the authors of the review

disagreed as they found many similarities in the health beliefs held by different ethnic groups. For example, the majority of participants' perceived hypertension was an illness associated with stress (Marshall, Wolfe and McKevitt, 2012). As a result, the authors concluded there was not strong enough evidence for interventions for hypertension to be tailored for particular cultural or ethnic groups but they should rather focus on common experiences.

There were a number of limitations with this review. The majority of the studies were conducted in the United States, some ethnic groups were over represented (African Americans) and a lack of information was available regarding South Asian participants included in the review, if any. The recommendation of not culturally adapting interventions for cultural and ethnic groups relates to the content provided on interventions. The recommendation does not comment on culturally adapting interventions with regards to delivery, such as using community languages or adopting a didactic or facilitative educational approach. Therefore, the findings in the aforementioned review are not wholly applicable to South Asian communities residing in the UK.

When treating first generation South Asian people, health professionals should ask patients whether they would like to bring their children to consultations/group interventions. Some patients prefer family members to be present in health care decisions (Katbamna *et al.*, 2004) and children attending interventions may also gather a better understanding of how their parents/grandparents feel about living with chronic diseases.

This research has identified that a relationship exists between religious faith and perceptions towards self-management and behavioural change for people from BME groups. Rather than

acting as a barrier to self-management, health professionals could encourage patients to use prayer/meditation as tools to cope with the emotions associated with living with chronic disease. A summary of the main recommendations for practice and policy are detailed in Table 26.

Table 26. Summary of recommendations for practice and policy

Recommendations for policy and practice
CDSMPs should be culturally adapted for first generation migrants from South Asian communities with regards to delivery and content
Self-management interventions need to test whether participants have understood the content provided on programmes
Longer term follow-ups are required to determine the effectiveness of self-management interventions for minority-ethnic groups
Lay educators can be used to deliver self-management interventions to a socio-economically disadvantaged multi-ethnic population

9.7 RECOMMENDATIONS FOR FURTHER RESEARCH

The various approaches/methods used and participants included throughout my research have helped me to recognise the need for further research across a number of areas. The most significant of these are considered evaluating the potential contribution each suggestion would make. A summary of the recommendations for further research are presented in Table 27 and are discussed in more detail in the following text.

Table 27. Summary of recommendations for further research

Recommendations for further research
Investigate the attitudes of people who drop out or decline the opportunity to attend self-management interventions
Establish guidelines outlining the training needs of lay people delivering services to people living with chronic diseases from deprived and/or minority-ethnic groups
Evaluate the value of visual aids within health education interventions
Determine the effectiveness of cultural adaptations upon clinical and cognitive outcomes
Seek evidence with regards to the acceptability of home-based exercise within South Asian communities
Conduct randomised controlled trials measuring the effectiveness of CDSMPs in South Asian populations
Develop a greater understanding of behaviour change and self-management in faith-based communities

Firstly, the attitudes of individuals who do not attend or drop out of self-management programmes should be evaluated. This would help to ascertain reasons for non-attendance and potentially identify aspects of health services which may be unsuitable for people living with chronic diseases. This may have particular importance for men living with chronic conditions as they are less likely to attend interventions compared to women.

The attitudes of CDEs and data collected from observations highlighted the need for further investigation into the training needs of lay people delivering services for people living with chronic conditions. There have been many assessments of lay people delivering interventions; however, there are no formal guidelines for lay people on how to deliver self-managements interventions for minority-ethnic groups.

The application and use of visual aids as a method of delivering health information for poorly educated individuals is an interesting area for further development. Traditionally, interventions had been designed to meet the cultural and linguistic requirements of their participants but they should also extend to address participant learning needs. It would be interesting to evaluate and compare behavioural change interventions which provide content through visual/audio material and those which are more text dependent.

A quantitative evaluation of the effectiveness of cultural adaptations used in behavioural change interventions would be valuable. Although my research recognises the role of cultural adaptations in the learning experience for people from disadvantaged backgrounds, specifically measuring their impact upon clinical and cognitive outcomes would add to the current evidence base.

Meanings and interpretations of exercise amongst members of South Asian communities remains a significant area for investigation. South Asian participants included in this study were still likely to spend very little time exercising and more likely to identify household tasks as physical activity. Consequently, South Asian participants should be asked about their preferences for home-based exercise and which type of exercises they prefer e.g. yoga.

Engaging greater South Asian patient and public involvement with research remains an area for development. Minority-ethnic groups need to be informed about the role and purpose of health research while academic institutions should establish ties with community-based organisations.

Findings from the systematic review suggest more randomised controlled trials need to be conducted measuring the effectiveness of chronic disease self-management with minority-ethnic groups. Only a single RCT has been conducted with a minority-ethnic group in the UK (Griffiths *et al.*, 2005). Ideally, comparators should be one-to-one interventions or interventions delivered to non-minority-ethnic groups.

Understanding behaviour change and self-management in other faith-based communities would provide the opportunity to extend the theory of systems of support. As religion and community values were seen to influence self-management behaviours in the Sikh community, a greater understanding in other faith-based communities could potentially identify new barriers and/or facilitators to living a healthy lifestyle.

More research studies should be conducted which endeavour to understand how people living with chronic conditions and from socio-economically disadvantaged and/or minority-ethnic groups interpret the process of making behavioural changes. Greater priority should be placed on interpreting the role of social and political factors upon behavioural change and health and well-being. Specifically, greater attention should be given to qualitatively assessing the community-level impact of local and national health policy regarding health promotion e.g. the Change 4 Life campaign by the UK government.

9.8 LIMITATIONS OF FINDINGS

A final report of the evaluation of the Chronic Disease Educator programme was submitted to Birmingham and Solihull NHS Cluster (which the former Heart of Birmingham Primary Care Trust is now part of) in July 2012. Due to the submission of this thesis, the impact of the report on the commissioning of local health services is not known and therefore not reported. However, informal feedback from commissioners welcomed the meticulous reporting of findings and appreciated the systematic review which provides an evidence base for the suitability of CDSMPs within Birmingham.

During the three years it took to carry out this study, I faced a number of challenges. The evaluation was likely to influence whether the CDE intervention would be re-commissioned and consequently the providers of the service (Health Exchange) may have attempted to show the positive side of the programme. Nevertheless, this was countered by accounts provided by lay educators who remained critical of the management structure at the time of data collection.

Data was collected over a considerable length of time (January 2010 to September 2011). Since data collection the CDE programme has undergone a number of changes, for example, offering participants the opportunity to receive health information one-to-one with lay educators if participants decide the original group format is unsuitable. However, the content, group format and implementation of the programme remain the same. Data collected at the beginning of the study (interviews with lay educators) was not as rich as data collected later in the study (interviews with participants and the Sikh community). This perceived lack of richness was due to my interview skills being in their infancy, where later interviews were

conducted once I had undergone greater qualitative research training. Data collection was protracted due to an application for ethical approval (interviews with Sikh community) and not knowing whether I would be able to observe one lay educator. In addition, I was reliant on Health Exchange to organise suitable times to interview CDEs, observe the programme (when and where) and provide the details of participants to interview.

Within interviews I was often interrupted; members of a participant's family were walking into the interview room, phones ringing, and even dogs barking! Therefore, I had to continue to work through or around such interruptions. Interviews with members of the Sikh community required greater cultural sensitivity; exploring concepts entrenched within religious beliefs and cultural customs e.g. the concept of *Seva* [selfless service], as well as discussing caste without portraying any signs of judgement or discrimination. Finally, it was often difficult to generate detailed responses from participants and I had to be imaginative in the way I asked questions. For instance, with interviews with participants who completed the CDE programme, a greater depth of answer was obtained when people were asked what they enjoyed about the programme and what could have been better rather than directly asking what participants liked or disliked.

9.8.1 Personal reflections on the production of my thesis

I have included a reflexive account in Chapter 3 so other researchers reading my findings can acknowledge and understand the steps I adopted to undertake this project. In Appendix 13 I also describe the involvements of colleagues in the production of this thesis. Here I present general reflections on the production of my thesis. I found the experience of learning about chronic disease and self-management equally enjoyable and frustrating. CDSMPs may be a

relatively recent phenomenon, but the scope of the topic is broad. Interpreting data and developing themes was my biggest challenge as it took time to build my confidence of using qualitative methods and being able to demonstrate my findings were not simply the product of personal subjective interpretations. Using the work of Paulo Freire, Michael Foucault and medical sociologists helped to critically engage with data and its relevance to health services research.

On reflection, many of the difficulties I faced may have been avoided if I acknowledged the effort required to undertake qualitative research prior to starting my project. A greater amount of time spent developing my qualitative skills and building a secure grounding in qualitative methodology would have been valuable. Having a background in Sociology was helpful, as it enabled me to comprehend the wider social factors at play with regards to self-management and not simply focus on individual agency. The most enjoyable (but initially most daunting) aspect of the past three years was meeting and interviewing participants living with chronic diseases. This was my first opportunity to listen to personal accounts of how chronic diseases change a person's perception of self, as well as their physical and emotional well-being. Interviewing people from different genders, ages, ethnic and religious groups provided an insight into illuminating narratives, constructed by patterns of migration, community values and relationships people had with others. Having completed this thesis, I look forward to developing some of the ideas presented in the recommendations for further research section.

9.9 CONCLUDING REMARKS

In conclusion, this thesis has provided a greater understanding of chronic disease and self-management, and provided a greater theoretical insight into the design of self-management

interventions for socio-economically disadvantaged multi-ethnic populations. The inclusion of a detailed descriptive theory-based evaluation provided the opportunity to assess the effectiveness of cultural adaptations used in self-management interventions designed for multi-ethnic populations.

Throughout this thesis a number of contributions have been made to existing literature. Firstly, the systematic review presented in Chapter 3 details comprehensive reporting criteria for lay people delivering self-management interventions and CDSMPs. Furthermore, the taxonomy of cultural adaptations is the first to consider the social, cultural and behavioural significance of cultural modifications used in interventions for minority-ethnic populations living in high income countries. The taxonomy is a valuable tool which can be used when developing self-management interventions for minority-ethnic populations in the future.

Secondly, the effectiveness of cultural adaptations was assessed using a mixed methods approach in a chronic disease self-management programme attended by South Asian (Indian, Bangladeshi, and Pakistani), Black Caribbean, and White British participants. In addition, interviews with lay educators explored new areas of interest, such as the tasks and responsibilities lay people have beyond the delivery of workshops.

Thirdly, exploration of health beliefs with the Sikh community identified how perceptions towards self-management are constructed through lay and cultural systems of support. Importantly, membership to community and identity groups had a considerable influence on health-related behaviour with first, second and third generation individuals. As a result of this study a number of potential areas of further investigation have also been identified.

Collectively, the findings presented in this thesis make an important contribution to health services research.

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APPENDIX 1

Abraham and Michie (2008) 26 item behavioural change technique checklist with descriptions

1. Provide general information on behaviour-health link

Information about the relationship between the behaviour and health – including susceptibility or factual risk and/or mortality information OR. health education material relevant to the behaviour. NB Check that any instance does not also involve techniques 2 or 3.

2. Provide information on consequences

Involves providing information focusing on what will happen if the person performs the behaviour including the benefits and costs of action or inaction. NB Check that any instance does not also involve techniques 1 or 3.

3. Provide information about others' approval

Involves information about what other people think about the reader's or target person's behaviour. It clarifies whether others will like, approve or disapprove of what the person is doing or will do. NB Check that any instance does not also involve techniques 1 or 3.

4. Prompt intention formation

Involves encouraging the person to set a general goal or make a behavioural resolution e.g., "I will take more exercise next week" would count as a prompt to intention formation. This is directed towards encouraging people to decide to change. NB This is distinguished from technique 10 by the general nature of the goal i.e., it does not involve planning exactly what will be done or when the behaviour or action sequence will be performed. Where the text only states that goal setting was used without specifying the detail of action planning involved then this would be an example of this technique (not technique 10).

5. Prompt barrier identification

Think about potential barriers and plan ways of overcoming them. Barriers may include competing goals in specified situations. This may be described as “problem solving” and if it is problem solving in relation performance of the behaviour i.e., then it is an instance of this technique. NB Closely related to technique 10 but involves a focus on specific obstacles to performance. Techniques 5, 7 and 10 can be used independently or in combination – check for each separately.

6. Provide general encouragement

Involves praising or rewarding the person for effort or performance without making this contingent on specific behavioural performance; or “motivating” the person in an unspecified manner. This will include attempts to enhance self-efficacy through argument or persuasion (e.g., telling someone they will be able to perform a behaviour). NB Check distinction with techniques 14 and 16.

7. Set graded tasks

Set the person easy-to-perform tasks, making them increasingly difficult until target behaviour is performed. NB Although this might follow from technique 10, the key difference lies in planning to perform a sequence of preparatory actions or task components which increase in difficulty over time - as opposed to simply planning out a sequence of actions in detail.

8. Provide instruction

Involves telling the person how to perform a behaviour or preparatory behaviours. For example, providing individual face to face instructions, offering an instructional group class or providing “tips” on how to take action in text form. NB Check whether there are also instances of techniques 4, 5, 7, 9 or 10.

9. Model/ Demonstrate the behaviour

Involves showing the person how to correctly perform a behaviour e.g., face-to-face as in a group class or using video. NB This is distinct from just providing instruction (technique 8) because in “demonstration” the person is able to observe the behaviour being enacted. Techniques 8 and 9 may be used separately or together – check for this.

10. Prompt specific goal setting

Involves detailed planning of what the person will do including, at least, a very specific definition of the behaviour e.g., frequency (such as how many times a day/week), intensity (e.g., speed) or duration (e.g., for how long for). In addition, at least one of the following contexts i.e., where, when, how or with whom must be specified. This could include identification of sub-goals or preparatory behaviours and/or specific contexts in which the behaviour will be performed. NB Without clear illustration of this level of detail instances of “goal setting” should be regarded as applications of technique 4. Thus the terms “goal setting” or “personal plan” 4 are not enough to ensure inclusion of this technique. When specific goal setting is used this does not automatically imply technique 4. Both or either may be included in an intervention.

11. Prompt review of behavioural goals

Involves reconsideration of previously set goals/ intentions. In most cases this will follow previous goal setting and an attempt to act on those goals. NB Check that any instance does not also involve techniques 4, 7 or 10.

12. Prompt self-monitoring of behaviour

The person is asked to keep a record of specified behaviour/s. This could e.g., take the form of a diary or completing a questionnaire about their behaviour.

13. Provide feedback on performance

This involves either receiving data about recorded behaviour (e.g., following technique 12) or commenting on how well or badly a person has performed an action (e.g., identifying a discrepancy with a set goal – see techniques 4 and 10 – or a discrepancy in relation to the performance of others – note this could also involve technique 19). NB General praise which does not include comment on performance is included in technique 6.

14. Provide contingent rewards

This can include praise and encouragement as well as material rewards but the reward/ incentive must be explicitly linked to the achievement of specified goals i.e. the person receives the reward if they perform the specified behaviour (or preparatory behaviour) but not if they do not perform the behaviour. NB Check the distinction between this and techniques 6 and 13.

15. Teach to use prompts/ cues

Teach the person to identify environmental prompts which can be used to remind them to perform the behaviour. This could include times of day, particular contexts or elements of contexts which prompt them to perform the target behaviour. Note that this could be used independently or in conjunction with techniques 4 and 10.

16. Agree behavioural contract

Must involve agreement (e.g. signing) of an explicitly specifying behaviour so that there is a written record of the person's resolution witnessed by another.

17. Prompt practice

Prompt the person to rehearse and repeat the behaviour or preparatory behaviours numerous times. Note this will also include parts of the behaviour e.g., refusal skills in relation to quitting smoking. This could be described as "building habits or routines" but is still practice so long as the person is prompted to try the behaviour (or parts of it) during the intervention. NB If this is done in a group setting it will inevitably involve technique 19. Thus a group class in which people perform the behaviour or parts of the behaviour will include practice and opportunities for social comparison.

18. Use of follow up prompts

Involves sending letters, making telephone calls, visits or follow up meetings after the major part to the behaviour change intervention has been completed. If spaced contacts is an intrinsic part of the behaviour change intervention these in themselves do not count as follow

up. NB This may (but does not need to) involve general encouragement i.e. include an instance of technique 6.

19. Provide opportunities for social comparison

This will most commonly be seen in the case of group practice (e.g., group classes) but could also be employed using detailed case studies in text or video or by pairing people as supports. It provides a setting in which processes such as social comparison could occur. Social support may also be encouraged in such settings and this would then involve technique 20. Group classes may also involve instruction (technique 8) demonstration (technique 9) and practice (technique 17). Check for these additional techniques.

20. Plan social support/ social change

Involves prompting the person to think about how others' could change their behaviour to offer him/her help and/or (instrumental) social support. This will also include provision of such support during the interventions e.g., setting up a "buddy" system or other forms of support. NB This could (but does not need to) involve technique 5 – where others' behaviour are perceived to be a key barrier to successful performance. Techniques 5 and 20 can be used independently or together.

21. Prompt identification as role model/ position advocate

Involves focusing on how the person may be an example to others and affect their behaviour e.g., being a good example to children. Also includes providing opportunities for participants to persuade others of the importance of adopting/ changing the behaviour. For example, giving a talk or writing a persuasive leaflet.

22. Prompt self talk

Encourage the person to use talk to themselves (aloud or silently) before and during planned behaviours to encourage and support action.

23. Relapse prevention

Following an initial change help the person identify situations that increase the likelihood of returning to a risk behaviour or failing to perform a new health behaviour – and help them plan how to avoid or manage the situation so that new behavioural routines are maintained.

NB This may look like technique 5 but is distinct in that it occurs only after an initial change has taken place.

24. Stress management

This may involve a variety of specific techniques (e.g., progressive relaxation) which do not target the behaviour directly but seek to reduce anxiety and stress to facilitate the performance of the behaviour.

25. Motivational interviewing

This is a specific set of techniques involving prompting the person to provide self-motivating statements and evaluations of own behaviour to minimise resistance to change (includes motivational counselling). NB Normally this technique will be mentioned by name.

26. Time management

This includes any technique designed to help a person make time for the behaviour (e.g., how to fit it into a daily or weekly schedule). These techniques are not directed towards

performance of target behaviour but rather seek to facilitate it by freeing up times when it could be performed. This technique may or may not be mentioned by name.

APPENDIX 2

Electronic search strategy and search terms (MEDLINE), TI, KW, AB

- 1) Randomised Controlled Trial
- 2) Self-management- Self Care
- 3) Group Intervention- Self Help Groups, Self Care, Group Intervention
- 4) Group Education- Patient Education as topic, diabetes mellitus (type 2), Health Education, Self Help Groups, Group Education
- 5) Diabetes Mellitus- Diabetes Mellitus as topic, Diabetes Mellitus
- 6) Coronary Heart Disease- Coronary Disease, CHD
- 7) Arthritis- Arthritis, Rheumatoid Arthritis, Arthritis
- 8) Chronic Illness- Chronic Disease, Chronic Illness
- 9) Lay Educator- Community Health Aides, Health Education, Diabetes Mellitus, African Americans, Health Knowledge, Patient Education, Hispanic Americans, Lay Educator
- 10) South Asian- Diabetes Mellitus, Indian, Coronary Disease, Obesity, South Asian
- 11) Pakistan*- Pakistan, Diet, Hypertension, Pakistan*
- 12) Bangladesh*- Bangladesh, Bangladesh*
- 13) Black- African Cultural Ancestry Group, Black
- 14) Ethnic*- Ethnic Groups, ethnic*
- 15) 10 (South Asian- Diabetes Mellitus, Indian, Coronary Disease, Obesity, South Asian)
OR 11 (Pakistan*- Pakistan, Diet, Hypertension, Pakistan*) OR 12 (Bangladesh*- Bangladesh, Bangladesh*) OR 13 (Black- African Cultural Ancestry Group, Black)
OR 14 (Ethnic*- Ethnic Groups, ethnic*)
- 16) Non Randomised Controlled Trial
- 17) Before and After Stud*

- 18) 1 (Randomised Controlled Trial) OR 16 (Non Randomised Controlled Trial) OR 17
(Before and After Stud*)
- 19) 18 [1 (Randomised Controlled Trial) OR 16 (Non Randomised Controlled Trial) OR
17 (Before and After Stud*)] AND 2 [(Self-management- Self Care)
- 20) 3 [(Group Intervention- Self Help Groups, Self Care, Group Intervention] AND
4[(Group Education- Patient Education as topic, diabetes mellitus (type 2), Health
Education, Self Help Groups, Group Education]
- 21) 19 [1 (Randomised Controlled Trial) OR 16 (Non Randomised Controlled Trial) OR
17 (Before and After Stud*) AND 2 (Self-management- Self Care)] AND 20 [3
(Group Intervention- Self Help Groups, Self Care, Group Intervention) AND 4 Group
Education- Patient Education as topic, diabetes mellitus (type 2), Health Education,
Self Help Groups, Group Education]
- 22) 5 [Diabetes Mellitus- Diabetes Mellitus as topic, Diabetes Mellitus] OR 6 [Coronary
Heart Disease] OR 7 [Arthritis- Arthritis, Rheumatoid Arthritis] OR 8 [Chronic
Illness- Chronic Disease, Chronic Illness]
- 23) 19 AND 20 AND 22
- 24) 23 AND 9 [Lay Educator- Community Health Aides, Health Education, Diabetes
Mellitus, African Americans, Health Knowledge, Patient Education, Hispanic
Americans, Lay Educator]
- 25) Peer Educator- Peer Group, Health Education, Adult, Health Knowledge, Peer
Educator
- 26) 9 OR 25
- 27) 20 AND 26
- 28) 27 AND 15

- 29) 28 AND 22
- 30) 29 AND 2
- 31) 30 AND 18
- 32) Group (Title)
- 33) Lay (Title)
- 34) 32 AND 33
- 35) Self-management (Title)
- 36) 34 AND 35-
- 37) Patient Education (Title)
- 38) 37 AND 32
- 39) 37 AND 33
- 40) 37 AND 35
- 41) Education (Title)
- 42) Diabet* (Title)
- 43) Arthritis (Title)
- 44) Coronary Heart Disease (Title)
- 45) 42 OR 43 OR 44
- 46) 41 AND 45

APPENDIX 3

Participant information sheets

1. Information sheet for Chronic Disease Educators (pg.413)
2. Information sheet participants who attended the CDE programme (pg.414)
3. Information sheet for members of the Sikh community (pg. 415)

Chronic Disease Educator Information Sheet

Purpose of this Evaluation

This evaluation forms part of the overall evaluation of the Chronic Disease Educators (CDE) service. The aim is to explore the views of CDEs about their particular role and the service, how they deliver programme sessions to participants with chronic illnesses and the experience of group based health education.

Information Collection

The evaluation will consist of conducting semi-structured interviews with all of the CDEs currently on the programme. The interviews will be audio-taped and transcribed. Also group sessions will be observed with the aid of a research instrument to record information. The period of data collection will be approximately 1-2 months, as sessions are spaced weekly.

Participation

Participation with this evaluation will be based around your working commitments, whereby times for data collection can be arranged accordingly. Involvement in the evaluation will not impact upon your employment status with Health Exchange and you have the right to withdraw your participation at anytime.

Confidentiality

All information provided throughout the this evaluation is protected under the *UK Data Protection Act (1998)*, as a result information will only be used by those on the service evaluation team and not disclosed to third parties. The evaluation will do its utmost to preserve your anonymity and keep comments unidentifiable, therefore your names will not be mentioned. If you have any concerns regarding the information you give, you can ask to see the research instruments used to collect data and observe the final report before submission.

If you have any questions feel free to email me: Manbinder Sidhu

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Chronic Disease Educator: Patient Information Sheet

Purpose of this Evaluation

The University of Birmingham is evaluating the Chronic Disease Educator (CDE) service on behalf of Heart of Birmingham Primary Care Trust. As part of this evaluation we are seeking the views of patients who attended the programme.

Information Collection

The evaluation will consist of conducting in-depth interviews with patients who recently completed the programme. The interview will be audio-taped and typed up. If English is not your first language a bi-lingual interpreter can be requested with appropriate language skills.

Participation

Participation in this evaluation will be based around your working commitments, whereby times for interviews can be arranged for your convenience. Involvement in the evaluation will not affect the care you receive from the NHS. You have the right to withdraw your participation at anytime. There are no known risks in taking part in this study.

Confidentiality

All information provided throughout this evaluation is protected under the *UK Data Protection Act (1998)* and will only be used by those on the evaluation team. The evaluation will do its utmost to preserve your anonymity and keep comments unidentifiable, therefore your names will not be mentioned. If you have any concerns regarding the information you give, you can ask to see a typed copy of your interview.

If you have any questions feel free to email me: Manbinder Sidhu

[Redacted contact information]

Health Beliefs and Behaviours: Information Sheet

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

What is the purpose of the study?

We would like to understand health beliefs and behaviours in the Sikh community in Birmingham and find out your views about the best ways to help people to manage their illnesses (such as type 2 diabetes, heart disease and kidney disease)

Why have I been chosen?

People of South Asian descent are more likely to develop and suffer from long-term illnesses than other ethnic groups in the U.K. There has been limited research carried out with the Sikh community explaining how long term illnesses are managed and understood. We have invited you (and your family) so we can gather your views on your existing health behaviour and what model of care you would prefer to help you to manage your condition (if any).

What will happen to me if I take part?

The research will consist of conducting one-to-one in-depth interviews with members of the Sikh community. The interview will be audio-taped and typed up. If English is not your first language a researcher can be requested with appropriate language skills (Punjabi speaker)

Do I have to take part?

It is up to you to decide whether or not to take part. Participation in this research will be based around your working commitments, whereby times for interviews can be arranged for your convenience. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive from the NHS.

What are the possible disadvantages and risks of taking part?

We do not anticipate any risks in taking part in this study.

What are the possible benefits of taking part?

The information you give will help us to understand the most appropriate model of care to self manage and prevent the development of long-term illnesses in the Sikh community. You may also be given information about other health services which may benefit you.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical procedures and all information about you will be handled in confidence. All information provided throughout this research is protected under the UK Data Protection Act (1998) and will only be used by those on the research team. The study will do

its upmost to preserve your anonymity and keep comments unidentifiable, therefore your names will not be mentioned in any report of this research. A letter will also be sent to your GP confirming your participation in this study.

What will happen to the results of the research study?

No individual will be able to be identified in the published information. No person would be able to be identified in any published report.

Who is organising and funding the research?

This study is funded by the National Institute for Health Research (NIHR) and the Collaborations for Leadership in Applied Health Research and Care (CLAHRC). This study is conducted by the University of Birmingham with Heart of Birmingham Primary Care Trust.

Who has reviewed the study?

This study has been reviewed by a local research ethics committee.

What if I have a complaint about this study?

If you have a complaint about this study you can phone Dr Kate Jolly on 0121 414 7552 who is overseeing the research, or the usual NHS complaints procedure is available to you. You can also contact the Patient Advice and Liaison Service on 0121 627 8820 or email pals@uhb.nhs.uk.

Further questions

If you would like any more information

APPENDIX 4

Interview guides

1. Interview guide used for interviews with Chronic Disease Educators (pg.418)
2. Interview guide used for interviews with participants who completed the CDE programme (pg.422)
3. Interview guide used for interview with participants recruited from the Sikh community (pg. 426)

Research Instrument for Chronic Disease Educator Semi-Structured interviews

Participant Details

Participants name:

Age:

Location of session:

Ethnic origin:

Whether they live locally:

Date they began employment with Health Exchange:

Completed Foundation Degree at Matthew Boulton College (MBC):

Background

1. Can you tell me how you came to know about Health Exchange and the role you are currently doing?
2. Have you previously worked in the health sector before this position? *(ask only if this question has not been answered in the previous question)*
3. Why did you decide to become a Chronic Disease Educator? What was attractive about the position?

Structure of the Sessions/Programme

4. How are the CDE sessions planned- do you tend to follow the Health Exchange handbook?
5. Do you make any adjustments to the session content/layout? *What are they- cultural, social, religious changes? Does the CDE have any influence on the content of the sessions- would they like to have greater involvement?*
6. Do you have to meet any targets within the programme? *(what are these targets, how does it affect their role- pressure, less time educating)*

Group Dynamics

7. How do you like to deliver your sessions to the patients involved in the programme? *(one-to-one, group activities, lecturing, mixing pts into groups, making it enjoyable- informal approach- jokes)*
8. Do you actively seek to mix groups? *(why- more effective in changing pts behaviour and/or attitudes- how- ethnicity, language, age, gender)*
9. Are you wary of one person dominating the group- can you give an example?
10. What did you do to tackle any possible power relations?

Language

11. Are there any advantages or disadvantages for being bi-lingual (or non-bi-lingual)?
12. Is the session more or less effective through the use of interpreters?
13. Are the interpreters simply seen as an aid to the sessions?
14. Which groups or patients do you feel that you have the biggest impact upon when trying to change their dietary behaviour and attitudes? *(is language or ethnicity a fundamental factor in this?)*

Attitudes

15. What are your opinions upon the content of the sessions? *(easy/hard to teach, will it have an impact on patients, too 'wishy-washy')*
16. How do you feel about teaching these sessions to the community that you are from? *(more comfortable/ uncomfortable)*
17. Would you feel more comfortable teaching to another group of patients? Why?
18. What are your opinions of the Health Exchange Management? *(initially, have they changed, are they helpful-how- what would they change)*

19. Overall what are opinions of the programme itself? *(is it simply a stepping ladder for something else or long term position?)*

Theoretical Application

20. Are there any barriers to understanding for the patients?

21. What do you think the biggest barriers to understanding are for the patients involved in the programme? *(does not have to be programme specific- incorporate other social factors if possible)*

Research Instrument for Chronic Disease Educator programme: Participant interviews

Participant Details

Participants name:

Age:

Ethnic origin:

Background on patient

1. I understand you were invited to the CDE programme which is run for people with heart disease, diabetes or kidney disease. Can you tell me about the condition that you have?

How long have you suffered from this?

(Sub-questions)

What are your conditions?

What were you doing to manage your condition?

What impact was it having on your life- social; work; family

Had you used any other NHS services?

Reasons for participating in a group-based health education programme

2. What were your expectations of the programme? (immediate relief; cure; greater knowledge; tips and techniques)

(Sub-questions)

Advice on specific problem with condition

Wished to help others

Group-based education

3. Can you tell me what happened within sessions? (the role of the educator; the patients role; activities; leaflets)
4. How did you feel about the group approach? (talking in front of men/women; members of the same ethnic group; prefer 1-2-1 style)
5. Could you relate to other members of the group? (*female/male; similar condition; ethnicity/ religion; age- peer identification*)

Content and delivery

6. What were your opinions of the educator? (*the style in which they delivered the information; were they empathetic; were you able to build a bond with the educator*)

7. What did you make of the way the information was presented? (*didactic; participative; encouraging; humorous; teacher-like*)
8. What aspects of the programme did you most enjoy? (*learning new information; improve emotional well being; meeting new people suffering with similar conditions as themselves; being given the opportunity to narrate their personal experiences*)
9. What aspects of the programme did you least enjoy? (*dominant group members- not having the opportunity to talk; filling in questionnaires; group size- too large/ too small*)

Application of health information

10. Did you learn anything new from the programme? (what was it, has it made an improvement in their condition)
11. Who did you learn this information from? (educator; peers- the level of trust- assured)
12. How do you feel about managing your condition since the programme? (*positive outlook; no change; empowered; greater control; have there been any improvements- GP, social, psychological*)

13. Would you recommend this programme to other people? (*why/why not- positives/negatives- to which type of person would they recommend it to*)
14. What further support would you like now? (personalised approach; individual/group; seeing the same group again; more medical information; was this programme enough)

Research Instrument for Sikh Community: Semi structured interview

Participant Details

Participants name:

Generational cohort:

Occupation:

Views on health and advice

My ideas

- *What information would members of the Sikh community like to receive to manage their health (if any)?*

- *Who would they like this information from and why?- (lay people or medical professionals, values and meanings given to particular person)*

- *Where would they like to go to receive this support and information if it was available? – (GP surgery, community settings, within their homes, place of worship-suitability and appropriateness)*

Health and Lifestyle

1. In your opinion, what does a 'healthy lifestyle' consist of?

= *(what behaviours (or not) are involved; why is it important to maintain such behaviours; is this based on a healthy physical state and/or emotional state)*

2. Can you tell me about someone you know who you consider to be healthy and why you think they are healthy?

= *(does this mean being without an illness, physically active, appearance and shape)*

= *(are there behaviours they have adopted to remain healthy/ maintain their condition-specific dietary changes, exercises, meditation)*

3. Can you describe what you ate for breakfast today?

= *(ask the participant what they ate for other meals during the day and the different types of meals/food they would have within a 'normal' week)*

= *(more 'daal' or vegetables, consumption of meats and animal products, what are portion sizes like; foods that they may try to avoid; opinion on the difference of Western/ Asian diets)*

4. Can you tell me about the different cooking methods used within your household?

- *describe some meals that they (family members) prepare, the reasons behind practices- taste, 'healthy', 'filling', social occasions*

Knowledge about their condition

5. Can you tell me about the condition(s) that you have? (Can you tell me about a relative who suffers from an illness?)

- *(What do they think was the cause of your (or relatives) condition; what do they know about their condition)*

6. What are your views about heart disease/ diabetes?

- *(do they feel condition can be prevented, if so why; more likely to develop chronic conditions)*

7. Can you give me some examples about occasions when you (or your relative) have sought treatment for your (their) heart condition/diabetes and where you (they) went for help?
(general and acute periods)

- *(ask why they went to that particular place or person; what was positive/ negative, do they go to that place or person for all of their concerns with regards to their health; ask for descriptions of what the person helping them did)*
- *(what information is sought after from that particular person; did they consider going to alternative lay or medical people, and why they decided not to seek advice from that person)*
- *(ask about a time when they had not so serious condition/aliment and where they went for advice)*

8. Can you describe any occasions when you have had a good or bad experience of using any health services?

9. Can you give me some examples about times when you (or your relative) have had less serious conditions (e.g. headaches, cold, flu, minor physical injury, stress) and where you (they) went for help?

10. What services are you aware of with regards to receiving treatment or managing your health?

- *(are there any barriers or facilitators when accessing certain services from particular individuals)*

Religion and Culture

11. What impact (if any) has your (or relatives) condition had in your everyday life?

- *(emotional- can they recount a time when they have felt sad or 'depressed'; physical, social impacts- restriction; have you ever worried about developing the same illness as your relative?)*

12. What aspects of your health do you feel you should be responsible for?

- (discuss issues for what they are not responsible for- the role of government and legislation- price of foods)

13. What messages did your parents/grandparents tell you about foods and health (if any) when you were younger?

- (does the participant think these stories have an element of truth- if yes- why/why not; beliefs surrounding health bettering subcontinent, beliefs- impact on hot and cold foods etc...)

14. Other than your family, were there any other ways that you learnt about food and health?

15. How is your behaviour, with regards to staying healthy, different/similar to people of a different generation to yourself.

APPENDIX 5

Research instrument for observation

<u>Variable under Consideration</u>	<u>Area of Investigation</u>	<u>Time of observation</u>	<u>Observation</u>	<u>Further Questions/ Areas to investigate</u>
Background Information. (1)	Location: Date and Time: CDE: e.g. South Asian, male CDE Session: e.g. Introduction (1)			
	Interruptions:			
Group Dynamics (2)	Number of Participants:			
(3)	Characteristics of the group?			
(4)	Does the CDE mix individuals up? (ethnicity, gender, age, language- forced, reluctance, volunteer)			
(5)	Are there any groups that have formed? (by the CDE, naturally)			
(6)	Does the CDE bring in individuals who seem to be 'semi- excluded'? (who is excluded, why, what is done, one-to-one approach)			

(7)	Is there any patient ‘mapping’ to those that similar to them? <i>(similar patients interacting together)</i> <i>Peer identification (Trento:2001)</i>			
(8)	Are patient questions answered through the group or the CDE? <i>(evidence of patients informing each other, information through the CDE only)</i>			
Use of Language (9)	Is the CDE bi-lingual or English speaker only?			
(10)	Is there an interpreter present?			
(11)	Is the session constructed on the basis of language? <i>(separate those that need interpreter, slower pace)</i>			
(12)	Does the CDE adopt a formal/informal approach in regards to his/her language?			
(13)	Does the mixture of words provide a more complete picture? <i>(is it a useful aid in teaching/ hindrance to others)</i>			
(14)	Does the use of multiple langs break/create barriers to entry? <i>(confidence/confusion/inclusion/exclusion)</i>			

(15)	Is there any extensive use of emotive language by the CDE? <i>(feel, sad, happy, depressed)</i>			
(16)	Do CDEs or patients use certain words that may cause offence? <i>(fat instead of overweight, is it cruel/on purpose, racist, homophobic, avoiding words-how does CDE cope with it?)</i>			
(17)	Assess the body language of the CDE? <i>(positive- hand gestures, negative- arms crossed, does it change through the session)</i>			
(18)	How clearly does the CDE communicate? <i>(are they audible, clear, loud, draws attention to themselves)</i>			
(19)	Overall what are the CDEs strong qualities and what do they find challenging/difficult?			
Structure of sessions/ programme (20)	Are the aims and objectives clearly stated at the beginning of the session? How is this done?			
(21)	What is the teaching style adopted by the CDE? <i>(didactic, participative)</i>			
(22)	Does the teaching style change throughout the session? <i>(for diff. groups, speed things up, due to pt. needs-clarity)</i>			
(23)	Do teaching styles differ between CDEs that are bilingual and non-bilingual? <i>(how- more hand movements, pt involvement, greater structure,</i>			

	<i>'loose' format)</i>			
(24)	Are the sessions predominantly CDE led or group led in the session?			
(25)	Is there significant time spent in recording patient data? <i>(allocation of time to info, education, recording, activities)</i>			
Theoretical Questions (notes for debriefing) (26)	Is the programme a good application of the HBM, SCT, TPB, SDT or TTM? <i>(outline of the costs and benefits by pt)</i>			
(27)	Self-Efficacy: is there clear identification of outlining personal goals, patient evaluation, how high/low is patient confidence? <i>(inclusion of any social factors)</i>			
(28)	Are power relations clearly identifiable within the session?			
(29)	Do sessions outline the role of cultural norms and practices? How is this done?			
(30)	Issues/Factors relevant to the 'Patient Experience' of the CDE programme.			
(31)	Additional Information			

APPENDIX 6

Self-assessment patient questionnaires

APPENDIX 7

Participant information sheet (Punjabi translation)

ਸੀ ਐਲ ਦੇ ਐਚ ਆਰ ਸੀ ਬਰਮਿੰਘਮ ਐਂਡ ਬਲੈਕ ਕਮਿਊਨਟੀ (CLAHRC Birmingham & Black Country)

ਵਿਸ਼ਾ 6 - ਰੋਕਥਾਮ ਵਿਚ ਨਿਵੇਸ਼
ਯੂਨੀਵਰਸਿਟੀ ਆਫ਼ ਬਰਮਿੰਘਮ

ਸਿਹਤ ਬਾਰੇ ਵਿਸ਼ਵਾਸ ਅਤੇ ਵਿਹਾਰ: ਜਾਣਕਾਰੀ ਸੀਟ

ਅਸੀਂ ਤੁਹਾਨੂੰ ਇਸ ਖੋਜ ਅਧਿਐਨ ਵਿਚ ਭਾਗ ਲੈਣ ਲਈ ਸੱਦਾ ਦੇਣਾ ਚਾਹੁੰਦੇ ਹਾਂ। ਤੁਹਾਡੇ ਦੁਆਰਾ ਨਿਰਣਾ ਲੈਣ ਤੋਂ ਪਹਿਲਾਂ ਤੁਹਾਡੇ ਲਈ ਇਹ ਸਮਝਣਾ ਜ਼ਰੂਰੀ ਹੈ ਕਿ ਇਹ ਖੋਜ ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ ਅਤੇ ਇਸਦੇ ਵਿਚ ਤੁਹਾਡੇ ਲਈ ਕੀ ਸ਼ਾਮਲ ਹੋਵੇਗਾ। ਕਿਰਪਾ ਕਰਕੇ ਹੇਠ ਲਿਖੀ ਜਾਣਕਾਰੀ ਨੂੰ ਧਿਆਨ ਨਾਲ ਪੜ੍ਹਣ ਦੇ ਲਈ ਸਮਾਂ ਦਿਓ।

ਅਧਿਐਨ ਦਾ ਮਕਸਦ ਕੀ ਹੈ?

ਅਸੀਂ ਬਰਮਿੰਘਮ ਵਿਚਲੇ ਸਿੱਖ ਭਾਈਚਾਰੇ ਦੇ ਸਿਹਤ ਬਾਰੇ ਵਿਸ਼ਵਾਸਾਂ ਅਤੇ ਵਿਹਾਰਾਂ ਨੂੰ ਸਮਝਣਾ ਅਤੇ ਲੋਕਾਂ ਦੁਆਰਾ ਉਨ੍ਹਾਂ ਦੀਆਂ ਬਿਮਾਰੀਆਂ (ਜਿਵੇਂ ਕਿ ਮਧੂਮੇਹ, ਦਿਲ ਦੀ ਬਿਮਾਰੀ ਅਤੇ ਗੁਰਦੇ ਦੀ ਬਿਮਾਰੀ) ਨੂੰ ਸਹੀ ਤਰ੍ਹਾਂ ਠੀਕ ਕਰ ਸਕਣ ਵਿਚ ਮਦਦ ਕਰਨ ਦੇ ਸਭ ਤੋਂ ਵਧੀਆਂ ਤਰੀਕਿਆਂ ਦੇ ਬਾਰੇ ਤੁਹਾਡੇ ਵਿਚਾਰਾਂ ਨੂੰ ਜਾਣਨਾ ਚਾਹੁੰਦੇ ਹਾਂ।

ਮੈਨੂੰ ਕਿਉਂ ਚੁਣਿਆ ਗਿਆ ਹੈ?

ਯੂ. ਕੇ. (U.K.) ਵਿਚ ਹੋਰ ਭਾਈਚਾਰਿਆਂ ਦੇ ਮੁਕਾਬਲੇ ਦੱਖਣ ਏਸ਼ੀਆਈ ਪਿਛੋਕੜ ਵਾਲੇ ਲੋਕਾਂ ਦੇ ਲੰਬੀ ਅਵਧੀ ਤੱਕ ਚੱਲਣ ਵਾਲੀਆਂ ਬਿਮਾਰੀਆਂ ਨੂੰ ਵਿਕਸਤ ਕਰਨ ਅਤੇ ਉਨ੍ਹਾਂ ਨਾਲ ਗੁਸਤ ਰਹਿਣ ਦੀ ਵਧੇਰੇ ਸੰਭਾਵਨਾ ਹੁੰਦੀ ਹੈ। ਸਿੱਖ ਭਾਈਚਾਰੇ ਵਿਚ ਲੰਬੇ ਸਮੇਂ ਦੀਆਂ ਬਿਮਾਰੀਆਂ ਨੂੰ ਕਿਸ ਤਰ੍ਹਾਂ ਠੀਕ ਕੀਤਾ ਅਤੇ ਸਮਝਿਆ ਜਾਂਦਾ ਹੈ ਦਾ ਵਰਣਨ ਕਰਦੀ ਹੋਈ ਸੀਮਤ ਖੋਜ ਕੀਤੀ ਗਈ ਹੈ। ਅਸੀਂ ਤੁਹਾਨੂੰ (ਅਤੇ ਤੁਹਾਡੇ ਪਰਿਵਾਰ ਨੂੰ) ਸੱਦਾ ਦਿੰਦਾ ਹੈ ਤਾਂ ਕਿ ਅਸੀਂ ਮੌਜੂਦਾ ਸਿਹਤ ਸੰਬੰਧੀ ਤੁਹਾਡੇ ਵਿਹਾਰਾਂ ਅਤੇ ਤੁਹਾਡੀ ਤਕਲੀਫ਼ (ਜੇ ਕੋਈ ਹੈ) ਨੂੰ ਕਾਬੂ ਵਿਚ ਰੱਖਣ ਦੇ ਵਿਚ ਤੁਸੀਂ ਕਿਹੜੇ ਤਰੀਕੇ ਨੂੰ ਪ੍ਰਾਥਮਿਕਤਾ ਦੇਵੋਗੇ, ਬਾਰੇ ਤੁਹਾਡੇ ਵਿਚਾਰਾਂ ਨੂੰ ਇਕੱਠਾ ਕਰ ਸਕੀਏ।

ਜੇ ਮੈਂ ਭਾਗ ਲੈਣਾ/ਲੈਂਦੀ ਹਾਂ ਤਾਂ ਮੇਰੇ ਨਾਲ ਕੀ ਹੋਵੇਗਾ?

ਖੋਜ ਸਿੱਖ ਭਾਈਚਾਰੇ ਦੇ ਮੈਂਬਰਾਂ ਦੇ ਨਾਲ ਇਕੱਲੇ - ਨਾਲ - ਇਕੱਲੇ ਦੀਆਂ ਵਿਸ਼ੇਸ਼ਤਾ ਮੁਲਾਕਾਤਾਂ ਨੂੰ ਕਰਨਾ ਸ਼ਾਮਲ ਕਰੇਗੀ। ਮੁਲਾਕਾਤਾਂ ਨੂੰ ਆਡਿਓ ਟੇਪਾਂ ਉੱਤੇ ਰਿਕਾਰਡ ਕਰ ਲਿਆ ਜਾਵੇਗਾ ਅਤੇ ਟਾਈਪ ਕਰ ਲਿਆ ਜਾਵੇਗਾ। ਜੇ ਅੰਗਰੇਜ਼ੀ ਤੁਹਾਡੀ ਪਹਿਲੀ ਭਾਸ਼ਾ ਨਹੀਂ ਹੈ ਤਾਂ ਢੁਕਵੇਂ ਭਾਸ਼ਾਈ ਹੁਨਰਾਂ (ਪੰਜਾਬੀ ਬੋਲਣ ਵਾਲੇ) ਵਾਲੇ ਖੋਜੀ ਦੇ ਲਈ ਬੇਨਤੀ ਕੀਤੀ ਜਾ ਸਕਦੀ ਹੈ।

ਕੀ ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣਾ ਹੀ ਪਵੇਗਾ?

ਇਹ ਨਿਰਣਾ ਕਰਨਾ ਤੁਹਾਡੇ ਉੱਤੇ ਹੈ ਕਿ ਭਾਗ ਲਿਆ ਜਾਵੇ ਜਾਂ ਨਾ। ਇਸ ਖੋਜ ਵਿਚ ਸ਼ਮੂਲੀਅਤ ਤੁਹਾਡੀਆਂ ਕੰਮ ਕਾਰ ਪ੍ਰਤੀ ਪ੍ਰਤੀਬੱਧਤਾਵਾਂ, ਜਿੱਥੇ ਕਿ ਮੁਲਾਕਾਤਾਂ ਨੂੰ ਤੁਹਾਡੀ ਸਹੂਲਤ ਦੇ ਅਨੁਸਾਰ ਨਿਰਧਾਰਤ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ, ਦੇ ਅਨੁਸਾਰ ਨਿਰਧਾਰਤ ਹੋਵੇਗੀ। ਜੇ ਤੁਸੀਂ ਭਾਗ ਲੈਣ ਦਾ ਨਿਰਣਾ ਕਰਦੇ ਹੋ ਤਾਂ ਤੁਹਾਨੂੰ ਇਹ ਸੀਟ ਰੱਖਣ ਦੇ ਲਈ ਦਿੱਤੀ ਜਾਵੇਗੀ ਅਤੇ ਤੁਹਾਨੂੰ ਸਹਿਮਤੀ ਫਾਰਮ ਉੱਤੇ ਦਸਤਖਤ ਕਰਨ ਲਈ ਕਿਹਾ ਜਾਵੇਗਾ। ਜੇ ਤੁਸੀਂ ਭਾਗ ਲੈਣ ਦਾ ਨਿਰਣਾ ਲੈਂਦੇ ਹੋ ਤਾਂ ਵੀ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਕਾਰਨ ਦੱਸੇ ਬਿਨਾਂ ਇਸ ਵਿਚੋਂ ਹੱਟਣ ਦੇ ਲਈ ਆਜ਼ਾਦ ਹੋਵੋਗੇ। ਕਿਸੇ ਵੀ ਸਮੇਂ ਲਿਆ ਗਿਆ ਹੱਟ ਜਾਣ ਦਾ ਨਿਰਣਾ ਜਾਂ ਭਾਗ ਨਾ ਲੈਣ ਦਾ ਨਿਰਣਾ ਤੁਹਾਡੇ ਦੁਆਰਾ ਐਨ ਐਚ ਐਸ (NHS) ਤੋਂ ਪ੍ਰਾਪਤ ਹੋਣ ਵਾਲੀ ਦੇਖਭਾਲ ਦੇ ਪੱਧਰ ਨੂੰ ਪ੍ਰਭਾਵਿਤ ਨਹੀਂ ਕਰੇਗਾ। ਇਹ ਅਧਿਐਨ ਪੀਐਚ ਡੀ (PhD) ਦੀ ਯੋਗਤਾ ਦਾ ਹਿੱਸਾ ਹੈ।

ਭਾਗ ਲੈਣ ਦੇ ਨਾਲ ਸੰਭਾਵਤ ਨੁਕਸਾਨ ਅਤੇ ਜ਼ੋਖਮ ਕੀ ਹਨ?

ਅਧਿਐਨ ਵਿਚ ਭਾਗ ਲੈਣ ਦੇ ਲਈ ਅਸੀਂ ਕਿਸੇ ਜ਼ੋਖਮ ਦੀ ਆਸ਼ਾ ਨਹੀਂ ਕਰਦੇ ਹਾਂ।



ਭਾਗ ਲੈਣ ਦੇ ਸੰਭਾਵਤ ਲਾਭ ਕਿਹੜੇ ਹਨ?

ਤੁਹਾਡੇ ਦੁਆਰਾ ਸਾਨੂੰ ਦਿੱਤੀ ਗਈ ਜਾਣਕਾਰੀ, ਸਾਨੂੰ ਸਿੱਖ ਭਾਈਚਾਰੇ ਦੇ ਵਿਚ ਲੰਬੀ - ਅਵਧੀ ਦੀਆਂ ਬਿਮਾਰੀਆਂ ਦਾ ਖੁਦ ਪ੍ਰਬੰਧਨ ਕਰਨ ਦੇ ਸਭ ਤੋਂ ਢੁਕਵੇਂ ਤਰੀਕੇ ਅਤੇ ਇਨ੍ਹਾਂ ਦੀ ਵਾਧੇ ਦੀ ਰੋਕਥਾਮ ਨੂੰ ਸਮਝਣ ਵਿਚ ਮਦਦ ਕਰੇਗੀ। ਤੁਹਾਨੂੰ ਹੋਰ ਸਿਹਤ ਸੇਵਾਵਾਂ ਦੇ ਬਾਰੇ ਵੀ ਜਾਣਕਾਰੀ ਦਿੱਤੀ ਜਾ ਸਕਦੀ ਹੈ, ਜੋ ਤੁਹਾਨੂੰ ਲਾਭ ਪਹੁੰਚਾ ਸਕਦੀ ਹੈ।

ਕੀ ਮੇਰੇ ਦੁਆਰਾ ਅਧਿਐਨ ਵਿਚ ਭਾਗ ਲੈਣਾ ਗੋਪਨੀਯ ਰੱਖਿਆ ਜਾਵੇਗਾ?

ਹਾਂ। ਅਸੀਂ ਨੈਤਿਕ ਪ੍ਰਕ੍ਰਿਆਵਾਂ ਦੀ ਪਾਲਣਾ ਕਰਾਂਗੇ ਅਤੇ ਤੁਹਾਡੇ ਬਾਰੇ ਦੀ ਸਾਰੀ ਜਾਣਕਾਰੀ ਨੂੰ ਭਰੋਸੇਯੋਗਤਾ ਦੇ ਨਾਲ ਸਾਂਭਿਆ ਜਾਵੇਗਾ। ਇਸ ਖੋਜ ਦੇ ਵਿਚ ਮੁਹੱਈਆ ਕਰਵਾਈ ਗਈ ਸਾਰੀ ਜਾਣਕਾਰੀ *ਯੂ ਕੇ ਡਾਟਾ ਪ੍ਰੋਟੈਕਸ਼ਨ ਐਕਟ (1998) (UK Data Protection Act 1998)* ਦੇ ਅਧੀਨ ਸੁਰੱਖਿਅਤ ਕੀਤੀ ਗਈ ਹੈ ਅਤੇ ਕੇਵਲ ਉਨ੍ਹਾਂ ਦੁਆਰਾ ਵਰਤੀ ਜਾਵੇਗੀ ਜੋ ਖੋਜ ਟੀਮ ਵਿਚ ਸ਼ਾਮਲ ਹੋਣਗੇ। ਅਧਿਐਨ ਤੁਹਾਡੀ ਗੋਪਨੀਯਤਾ ਨੂੰ ਸਾਂਭਣ ਅਤੇ ਟਿੱਪਣੀਆਂ ਨੂੰ ਅਪਛਾਣਯੋਗ ਬਣਾਉਣ ਦੇ ਲਈ ਇਸਦੀ ਪੂਰੀ ਕੋਸ਼ਿਸ਼ ਕਰੇਗਾ, ਇਸ ਲਈ ਇਸ ਅਧਿਐਨ ਦੀ ਕਿਸੇ ਵੀ ਰਿਪੋਰਟ ਦੇ ਵਿਚ ਤੁਹਾਡਾ ਨਾਮ ਨਹੀਂ ਦੱਸਿਆ ਜਾਵੇਗਾ। ਇਸ ਅਧਿਐਨ ਵਿਚ ਭਾਗ ਲੈਣ ਦੀ ਪੁਸ਼ਟੀ ਕਰਦਾ ਇਕ ਪੱਤਰ ਤੁਹਾਡੇ ਜੀਪੀ (GP) ਨੂੰ ਵੀ ਭੇਜਿਆ ਜਾਵੇਗਾ।

ਖੋਜ ਅਧਿਐਨ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਕੀ ਬਣੇਗਾ?

ਕੋਈ ਵੀ ਵਿਅਕਤੀ ਪ੍ਰਕਾਸ਼ਿਤ ਕੀਤੀ ਜਾਣਕਾਰੀ ਦੇ ਵਿਚ ਪਛਾਣੇ ਜਾਣ ਦੇ ਯੋਗ ਨਹੀਂ ਹੋਏਗਾ। ਕੋਈ ਵੀ ਵਿਅਕਤੀ ਪ੍ਰਕਾਸ਼ਿਤ ਕੀਤੀ ਗਈ ਕਿਸੇ ਵੀ ਰਿਪੋਰਟ ਦੇ ਵਿਚ ਪਛਾਣੇ ਜਾਣ ਦੇ ਯੋਗ ਨਹੀਂ ਹੋਏਗਾ।


ਖੋਜ ਕੌਣ ਕਰਵਾ ਰਿਹਾ ਹੈ ਅਤੇ ਕੌਣ ਇਸਨੂੰ ਵਿੱਤ ਦੇ ਰਿਹਾ ਹੈ?

ਅਧਿਐਨ ਨੈਸ਼ਨਲ ਇੰਸਟੀਚਿਊਟ ਫਾਰ ਹੈਲਥ ਰਿਸਰਚ (ਐਨ ਆਈ ਐਚ ਆਰ) (National Institute for Health Research, NIHR) ਅਤੇ ਕੋਲੈਬੋਰੇਸ਼ਨਜ਼ ਫਾਰ ਲੀਡਰਸ਼ਿਪ ਇਨ ਐਪਲਾਈਡ ਹੈਲਥ ਰਿਸਰਚ ਐਂਡ ਕੇਅਰ (ਸੀ ਐਲ ਏ ਐਚ ਆਰ ਸੀ) (Collaborations for Leadership in Applied Health Research and Care, CLAHRC) ਦੁਆਰਾ ਵਿੱਤ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ। ਇਹ ਅਧਿਐਨ ਯੂਨੀਵਰਸਿਟੀ ਆਫ਼ ਬਰਮਿੰਘਮ ਦੁਆਰਾ ਹਾਰਟ ਆਫ਼ ਬਰਮਿੰਘਮ ਪ੍ਰਾਇਮਰੀ ਕੇਅਰ ਟਰਸਟ (Heart of Birmingham Primary Care Trust) ਦੇ ਨਾਲ ਕਰਵਾਇਆ ਜਾ ਰਿਹਾ ਹੈ।


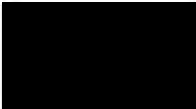
ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕਿਸ ਨੇ ਕੀਤੀ ਹੈ?

ਸਥਾਨਕ ਖੋਜ ਨੈਤਿਕਤਾ ਕਮੇਟੀ ਦੁਆਰਾ ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਗਈ ਹੈ।

ਤਾਂ ਕੀ ਜੇ ਮੈਨੂੰ ਇਸ ਅਧਿਐਨ ਦੇ ਵਿਰੁੱਧ ਸ਼ਿਕਾਇਤ ਹੋਵੇ?

ਜੇ ਤੁਹਾਨੂੰ ਇਸ ਅਧਿਐਨ ਦੇ ਬਾਰੇ ਸ਼ਿਕਾਇਤ ਹੈ ਤਾਂ ਤੁਸੀਂ ਡਾ. ਕੋਟ ਜੋਲੀ, ਜੋ ਇਸ ਖੋਜ ਦੀ ਦੇਖ ਰੇਖ ਕਰ ਰਹੇ ਹਨ, ਨੂੰ 0121 414 7552 ਉੱਤੇ ਫ਼ੋਨ ਕਰ ਸਕਦੇ ਹੋ ਜਾਂ ਤੁਹਾਡੇ ਲਈ ਐਨ ਐਚ ਐਸ ਦਾ ਸ਼ਿਕਾਇਤ ਕਰਨ ਦਾ ਸਧਾਰਣ ਤਰੀਕਾ ਉਪਲੱਬਧ ਹੈ। ਤੁਸੀਂ ਪੇਸ਼ਟ ਅਡਵਾਇਸ ਐਂਡ ਲਾਈਜ਼ਨ ਸਰਵਿਸ (Patient Advice and Liaison Service) ਨੂੰ  email pals@uhb.nhs.uk ਉੱਤੇ ਵੀ ਸੰਪਰਕ ਕਰ ਸਕਦੇ ਹੋ।

ਵਧੇਰੇ ਪੁੱਛਗਿੱਛ

ਜੇ ਤੁਸੀਂ ਵਧੇਰੇ ਜਾਣਕਾਰੀ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਮਨਖਿੰਦਰ ਸਿੰਘ ਨੂੰ (ਟੈਲੀ)  

APPENDIX 8

University of Birmingham Ethics Approval

APPENDIX 12

Dissemination of research

Oral presentations

1. Sidhu MS, Gale N, Jolly K, Gill P, Marshall T. *An analysis of current health beliefs towards chronic disease self-management and behavioural change interventions in a socio-economically deprived multi-ethnic population*, 10th Annual Meeting of The Quality Improvement Research Network (QIRN), Karolinska Institutet, Medical Management Centre, Stockholm, Sweden, June 2012
2. Sidhu MS and Duggal S. *The methodological implications for South Asian researchers interviewing South Asian participants: A reflexive description*, Using sociology to help prevent cardiovascular disease, University of Birmingham (in collaboration with National Institute of Health Research), Birmingham, UK, March 2012

Poster presentations

1. Sidhu MS, Gale N, Jolly. *A theory-based evaluation of a group-based lay-led chronic disease self-management intervention delivered in a multi-ethnic deprived population*, Using Sociology to help prevent cardiovascular disease, University of Birmingham (in collaboration with National Institute of Health Research), Birmingham, UK, March 2012
2. Sidhu MS, Gale N & Jolly K. *An evaluation of a group-based chronic disease self-management intervention delivered in a multi-ethnic deprived population*, Health Services Research Network and Service Delivery Organisation Network, Delivering better Health Services Conference, Liverpool, UK, June 2011

3. Sidhu MS, Gale N & Jolly K. *An evaluation of a group-based chronic disease self-management intervention delivered in a multi ethnic deprived population*, CLAHRC-BBC Dissemination Event, Birmingham, UK

APPENDIX 13

Involvement of colleagues in this research

Involvement of colleagues in this research

An initial outline of the study proposal, in relation to the evaluation of the Chronic Disease Educator programme, was designed by Professor Kate Jolly and Dr Nicola Gale in collaboration with Heart of Birmingham Primary Care Trust. However, I designed the nature of the evaluation, research questions, and which methods to implement. Professor Kate Jolly and Dr Nicola Gale provided feedback to Health Exchange about the design and selection of validated outcome measures used in participant self-reported questionnaires. With supervision from Professor Kate Jolly I undertook statistical analyses. I collected all qualitative data, conducted all coding, and developed themes with guidance from Dr Nicola Gale. I conducted systematic searches, independently read abstracts for inclusion (in duplicate with Professor Kate Jolly) and conducted data extraction along with Professor Kate Jolly, Dr Nicola Gale and Dr Paramjit Gill. Dr Tom Marshall reviewed the final draft of the systematic review and provided comments. I co-wrote a report of the evaluation of the Chronic Disease Educator programme with Professor Kate Jolly, Dr Nicola Gale, Dr Tom Marshall and Dr Paramjit Gill submitted to the Health Exchange and Heart of Birmingham Primary Care Trust. Any concerns arising from the conduct of the study were discussed with the CLAHRC-BBC Theme 6 steering group.