CULTURAL NEGOTIATIONS IN HEALTH AND ILLNESS: THE EXPERIENCE OF ADULT ONSET DIABETES AMONG GUJARATI SOUTH ASIANS IN ENGLAND

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ABSTRACT

Diabetes has become a global health problem, with both physical and psycho-social impacts on people's lives. The South Asian communities in the UK have been identified as 'high risk' groups with high rates of type 2 (non-insulin dependent) diabetes. This thesis explores the experiences of type 2 diabetes among a group of Hindu Gujaratis in several locations in England. Purposive and snowball sampling was used to recruit participants and a grounded theory framework was utilised to generate and analyse data. It is possible to suggest that health science discourse in a variety of forms has constructed a type of 'South Asian diabetic risk', alluding to a particular relationship between health and ethnicity. Through the use of qualitative methods participants in this research demonstrate active resistances to these constructions, through their accounts of diabetes management. By exploring the biographical, historical and socially embedded contexts that surround diabetes, participants constituted culture and ethnicity as dynamic entities, contingent on social, political and personal contexts. Within the context of qualitative methods, the role of the researcher and the various ways in which identities connect and need to be explicitly explored also forms a central idea within this work. This thesis highlights these active and dynamic constructions of cultural and ethnic identity. Health research needs to acknowledge the many varied ways in which people are able to manage their conditions as part of their overall social and cultural context. Situating health and illness experiences within a wider experiential field allows the possibility of fluid notions of identity to be implemented, and the relationship between health and ethnicity to be theoretically informed. These considerations may contribute to an understanding of how people manage their diabetes and where help and support might best be channelled.
To Mum and Dad
Thanks for all the stories.

To Asesha and Tayen
Thanks for all the stories that will be, looking forward to being forever in blue jeans.
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GENERAL INTRODUCTION

This thesis is about how a group of Hindu Gujarati people manage their experiences of type 2 diabetes and are able to use a variety of tools located in their social and cultural contexts to negotiate the landscape of their experience. The participants in this study were Gujarati speaking, British Asians, mainly Hindu, located in Leicester, Birmingham, Preston and Crawley, aged between 40 and 88.

The experience of diabetes holds particular purchase within the South Asian community because of the incidence and prevalence rates that exist in these communities. The thesis will aim to show that health science discourse over the last quarter of a century appears to have set up the research arena for these groups in a particular fashion, often using cultural and racial stereotypes, and employing static and rigid notions of identity, ethnicity and culture. It is these ‘constructions’ which this thesis seeks in part to highlight and which, as participants demonstrated through their accounts, appears to be ‘resisted’ through social action in the everyday management of diabetes and identity.

A range of aspects such as the conceptualisation of the illness, the diagnostic process, the role of diet, nutrition and exercise and help seeking for the condition, and the role of biographies and histories in connection with community and place were demonstrated as having impacts on people’s lives. These aspects however are not treated as isolated and static representatives of a medical model of disease management; rather they are situated within the social and cultural context of lived social action. For a sociological account, this involves locating the experience of type 2 diabetes within the complex web of interrelated parts of people’s lives, and allowing stories to emerge which provide an insight into how the people in this group actively negotiate the social, cultural and ethnic landscape of society, by using a variety of tools.
The picture rendered is not just a descriptive account of ‘what people do’. Rather what concerns this study is the role cultural, social and ethnic identity plays in facilitating the management and coping with of the disease. Locating the work within this framework also involves the exploration of migration related settlement experiences, biographies and existing connections the group have with the countries or continents they lived in (usually Africa and India). The stories which emerged in participant’s accounts framed the active construction of identity, rather than passive acceptance of identities which have been maintained by caricature and reification of concepts of minority cultures and groups.

Throughout the thesis concepts of ethnicity, culture and difference have been used critically, so that the dynamic ways in which these ideas are used in people’s everyday practices are reflected. It is these notions of difference and sameness which form the backbone of the methodology, and employ as their core concept a system of identity dialectics, showing how notions of identity within the research process are also subject to the ebb and flow of social action. This process of ‘cultural validations’, a process of engagement and interaction of researcher and participant identities, allows for the interconnectivity of biographies and identities by making explicit the relationship between researcher and researched. There is an invocation here of the possibility of treading on the wrong side of identity absolutism – i.e. you have to be a Gujarati Hindu South Asian to carry out the research and generate these findings. However, this is not the intention nor the stance taken within this study. The emphasis is on the role of cultural identity in research, and how various explicit connections between researcher and researched can, in the best traditions of general human relationships, enhance the research. It is not by polarising the argument between value-free, culture blind approaches and supposed authenticity that this debate can progress. Rather, unpacking the possible connectivities and what they mean and come to symbolise for all parties is where some interesting insights might be gleaned.

In exploring people’s experience of diabetes, this thesis looks at the situated nature of the condition, and the social and cultural contexts within which people constantly
make choices about seeking help, finding remedies, choosing allopathic and traditional medicines, and using their cultural identity to maintain personal and social selves, whilst dealing with the illness.

Overview of thesis

Chapter 1 locates the study within the general body of research in this area, and critiques a number of relevant areas — epidemiological, general health science related and sociological. The aim here is to frame the study so that firstly a ‘construction’ of South Asian risk can be discerned, and secondly a critique can be applied to the health science discourse which has generated this construction. The third aim is to situate the work within the interpretive sociological arena, examining a number of relevant and useful approaches.

Chapter 2 is an account of the general qualitative methodology employed within the study, and discusses both the philosophy and mechanics of the approach and its utility in this case. Here there is also a detailed account of the way in which grounded theory was called upon to generate samples, data and explanations for the findings.

Chapter 3 extends this understanding and frames epistemological concerns within the context of difference, culture, ethnicity and identity. The aim here is to examine in some detail the ways in which aspects of my identity - occupying researcher as well as other roles — interconnected with roles and identities held by participants, and the impact of this on the research. These ‘cultural validations’ informed the look of this thesis and is quite central to it, connecting with current debates within anthropology and sociology.

Chapters 4, 5 and 6 present the findings from the study, looking at: issues related to diagnosis, exercise and nutrition; the use of traditional and complimentary systems of remedies, and finally notions of identity, community and belonging. The themes in all three of these chapters are linked closely by the demonstration of active negotiations
of cultural identity. In a sense, they represent the ways in which despite the constructions of South Asian risk that have been built up over a long period of time, people 'resist' these discourses, and prove that they utilise the varied, social and cultural resources around them to accomplish social action.

The final two chapters, 7 and 8 pull the various strands of the thesis together, to discuss the interpretations of the data, and the theoretical and practical implications therein. Chapter 7 presents a discussion of where the data and their meaning actually sit in the theoretical field, and examines the various ways in which both sociological and anthropological theoretical frameworks can be used to locate their significance. Finally, chapter 8 concludes the thesis, reiterating the main arguments presented, and goes on to a critical look at the limitations of the thesis. Here a number of possible practical, methodological and conceptual limitations are discussed, as well as suggestions for developing the work further.
CHAPTER 1

DIABETES, EXPERIENCE AND ETHNICITY: A CRITICAL REVIEW

Introduction

This chapter will review a number of research areas – empirically and conceptually – which are relevant for this thesis and which provide a backdrop for the exploration of several research questions. A number of areas which are not sociological are also explored, because of the biomedical nature of the condition, and the epidemiological nature of its incidence and prevalence. This is carried out for the purpose of contextualising the overall sociological exploration in the thesis.

Firstly, after a general outline of the condition has been established, it is important to gain an insight into the general extent of diabetes in the South Asian population, given the high rate amongst this group as a whole is one of the rationales for this study. Most of this information is borne out of epidemiological and social epidemiological research, and provides an illness-extent base line picture.

Secondly, the relationship between ethnicity, culture and health will be explored, since the theoretical and methodological treatment of this area has a direct impact on the experiences of South Asian people with type 2 diabetes and on service provision. A key part of this section will look at the ways in which the collective health research discourse, which includes academic and policy arenas into diabetes and ethnicity, can be seen as ‘constructing a South Asian risk’. It is this ‘risk-identity’ which this thesis argues, is being resisted in the social and cultural interactions of people with type 2 diabetes. A central aim here will be to critically review literature which uses the cultural, lifestyle and genetic explanations to frame this risk.

The participants involved in the study are ‘lay’ people – whose experiences have been accounted for within interviews and field visit accounts. Therefore in the third section
it is appropriate to locate some useful and established ideas within the panoply of interpretive paradigms to explore lay experiences. Here notions of biography and lay ideas of health will be explored and critically discussed in light of the study aims.

The fourth section explores in some detail some specific sociological and diabetes experience work in order to provide a conceptual and experiential backdrop. This will look at some of the main ideas which have been contributed by both individual research and meta-reviews, and helps to situate this thesis.

The fifth section traces the link between diabetes experience and ethnicity, by examining some specific research within South Asian communities, and reviews these findings. This is part of the aim of this chapter which is to gradually build a picture of the experience of type 2 diabetes within South Asian communities but also to assess whether these contributions can make a theoretical statement about health and identity.

The final section then explores the extent to which contributions to this area have been able to provide not just description and analysis of diabetes accounts, but a theoretical location for the health and illness / agency and structure equation. Some of the research reviewed will form the theoretical backdrop to the study and will take some of these concepts as central to the overall thesis. This section will locate a number of approaches which look beyond reified categories of difference, and employ notions of culture and ethnicity as dynamic and malleable, according to the social and cultural needs of the individual. It is within this section that a discussion of theoretical approaches will take place, with an emphasis on those which provide a useful framework for the study.
1.1 WHAT IS DIABETES?

Diabetes Mellitus is a disease which affects the proper functioning of the body’s glucose levels. Insulin, a hormone normally naturally created by the pancreas is released into the bloodstream and regulates the levels of glucose in the blood. Glucose, a type of blood sugar which is vital for the body to transform into energy and various other uses, is usually maintained by the insulin at a level which is optimal for the body’s functioning. When food is eaten, the body changes most of the food intake into glucose. The blood then carries the glucose to cells in the body, to perform the pre-programmed instructions held in the genetic code. The glucose needs insulin to get into the body cells. In a diabetic patient, either the pancreas does not create enough insulin (or fails completely) or there is enough resistance to the insulin (in the form of receptor cells in the tissues of the body failing to utilise the insulin that is produced), to cause a malfunction, and this can lead to many complications, including kidney failure, neuropathology, retinopathy and death (Rubin 2001).

1.1.2 Types of diabetes

There are a variety of types of diabetes, but the two types which are the focus of much research are type 1 and type 2. There are other types of diabetes which are features of particular global and socio-political-economic conditions (famine related) or particular biomedical conditions, such as (gestational diabetes, common during pregnancy) – these are not the focus of this study.

Type 1 diabetes is an insulin dependent condition (IDDM – Insulin Dependent Diabetes Mellitus) which means that the individual’s body depends on an external source of insulin to regulate glucose levels. This condition is perceived to be serious in terms of prognosis, treatment, effects on the body’s functions and related life expectancy. Type 1 diabetes appears when the pancreas produces little or no insulin, causing the glucose levels in the blood to be without control. A dysfunction in insulin production can cause a variety of problems including fat and muscle formation
enhanced by insulin, storage of glucose and protein breakdown prevention. Type 1 is an auto-immune disease, whereby the insulin producing cells (beta cells) are destroyed by the body itself. Typical treatment is through a combination of medication, insulin (made from various sources, usually animal (pig) based, diet and exercise regimes.

Type 2 diabetes also known as non-insulin dependent diabetes mellitus (NIDDM) is the more common variety of diabetes. This condition is characterised by an insulin resistance syndrome which makes the processing of insulin and maintenance of glucose difficult. This condition is also known as Mature Onset Diabetes, as it usually appears or is diagnosed in later life, at around the age of 40 (although the number of younger people being diagnosed is increasing – especially in the South Asian communities – UK Prospective Diabetes Study Group 1994). The typical treatment for the condition is a regime of medication (usually tablets), nutritional and diet modification, exercise and the maintenance of lowered fat levels in the body (since increased body fat and obesity are said to cause deterioration of the condition). Although there is insulin being produced, the body resists the normal functioning of insulin - the *insulin resistance syndrome* – which can then lead to type 2 diabetes.

In terms of signs and symptoms, there are a number of commonalities between the two types which become a crucial part of the patient’s experiential knowledge base. Fatigue, frequent urination and thirst are common to both, but the differences are important. Type 2 symptoms also include blurred vision, slow healing of infections, numbness in extreme limbs, heart disease and obesity.

1.1.3 History

The term “diabetes mellitus” is a Greco-Latin term sourced in respective histories. The Romans found that sometimes urine would be sweet tasting - it tasted “mellitus” (Latin for ‘sweet’). Before this the Greek civilisation noted that sometimes people with this sweet urine produced fluids almost immediately, like a siphon and hence
called this condition “diabetes” (Latin for ‘siphon’, Rubin 2001). This early definition of the physical ailment was not limited to the Greek civilisation as Ancient Hindu texts as early as 1000 BC in recorded observations similar to that of the Romans much later, recall ants swarming near a spot of urine indicating ‘Madhumeha’ (honey urine), which if neglected could finally lead to ‘Prameha’ (Diabetes). Official Indian medical treatises also were being formed in 600 AD defining clearly the condition of diabetes mellitus – or – ‘Prameha’ (Subbulakshmi & Naik 2001), suggesting that while diabetes has moved to a world wide health agenda in modern times, it also has a long cultural and nation specific history.

1.1.4 Complications

Diabetes is an illness which has a series of possible complications if left untreated. Both type 1 and 2 diabetics run a risk of developing a certain number of established complications. Kidney problems, eye sight impairment, peripheral nerve damage of the extremities, and autonomous nerve system problems are all commonly reported problems. In the working population it is the most common cause of blindness, and a major cause of renal failure (Leedham 2000). While there is still no way of definitely avoiding these complications, the main point of treatment is to monitor blood glucose levels, maintain normalcy according to a pre-defined level and implement strategies of insulin level change. Diet, exercise, education and professional health advice are still the only methods of keeping the illness under some control.

1.2 MORTALITY & MORBIDITY

The literature on the experience of diabetic patients has been gradually increasing over the past 20 years. Much of the work has taken the form of important epidemiological studies, establishing prevalence and incidence rates (Barker et al 1982; WHO 1985; Jarrett 1986; Zimmet 1982). The British Diabetic Association also makes statements concerning the levels of undiagnosed diabetes within the UK currently at 1 million people (Amos et al 1997).
Diabetes is a global disease and the incidence rates vary hugely from one population to another and from East to West. In 2002, WHO reported that over 176 million people worldwide had diabetes, with projections increasing to over 370 million by the year 2030.

These figures demonstrate the huge burden of illness this disease is responsible for in purely epidemiological terms. For the purposes of this study, the focus will be on England, where the target population reside. In England the number of people with diabetes is estimated at 2.35 million, projected to grow to 2.5 million in the next 3 years, with 90% of people with diabetes having type 2. The incidence level in some parts of the country of type 2 diabetes is estimated to be growing at 15% a year.

Life expectancies for people suffering from diabetes are also reduced. For type 1 sufferers, 20 years are taken off the average life span, while for type 2 the amount their life duration is reduced by is 10 years, not including those serious and sometimes fatal complications of eye disease, renal failure and limb extremity neuropathology. This is highlighted further by diabetes being the main cause of renal failure in the UK (Department of Health 2002).

Epidemiology indicates that Black and South Asian populations are more vulnerable to diabetes than white counterparts, both in the UK and globally. As one of the most common chronic illnesses in the UK, type 2 diabetes has a particularly high rate in these communities. Type 2 diabetes is up to 5 times more common in the South Asian community compared to the White population (D’Costa et al 2000). People of South Asian origin are exposed to an increased risk of diabetes (Davies 1999) and present with diabetes at a younger age than Caucasians (McKeigue & Marmot 1988). This finding is supported by other more recent studies which indicates a three to five times higher risk amongst African-Caribbean and South Asian populations (Davey Smith 2002). While a variety of factors have been discussed and proposed as possible explanations for this apparent increased risk, there is still little agreement regarding conclusive answers.
South Asian groups are seen as not only high risk groups for developing diabetes, but studies have also shown that obesity is one of the strongest risk factors for type 2 diabetes. Other studies show there maybe some interaction between obesity and South Asian diabetes levels. People from South Asia were regarded as more likely to be at risk of diabetes than Caucasians (McKeigue et al 1991). Projections for Asia state that it will be home to 61% of the global burden. One of the biggest increases by 2010 will be South-Central Asia (57.5 million).

The significance of these figures is the global picture that is rendered – given the beliefs among people in the sample for this study that heredity is a strong factor in diabetes. Although biomedical, genetic and epidemiological research insists on gathering increasing amounts of evidence regarding the cause of diabetes, there is little agreement about the actual cause, or the significance of genetics and heredity. The significance here is held in the connections people in the sample maintained with their migration countries, and often the perceived causes people mentioned in relation to their condition were related to a ‘western’ lifestyle. In the CURES (Chennai Urban Rural Epidemiology Study) study, 22.3% of the population was defined as obese (the sample size was 26,000), with obesity increasing with monthly income (Deepa et al 2003) – a correlation of importance in the context of diabetes perceived globally as a disease of affluence. As the data will show, there is certainly a perception that simply being in the UK has adverse effects on people, one of them being developing diabetes.

The links between the overall burden of illness in India and the state of the illness in this country are more conceptual than epidemiological. The incidence and prevalence figures in this country are lower than those for India, though there is considerable evidence of a greater likelihood of diabetes diagnosis for the South Asian community. In the UK South Asians make up 3.9% of the total population of the UK, and 50.2% of the minority ethnic population (Black and Minority Ethnic (BME) groups making up 7.6% of the total UK population (Office of National Statistics 2005). Although this does not constitute a huge proportion of the population, specific research into BME health has shown an over representation of illness in these communities. Nazroo
(1997) demonstrated the huge variations in health in these communities. While many different indicators for health and illness were used, clearly demonstrating disparity in health status, the consistent theme was wide variations in and between ethnic groupings, with social class and socio-economic indicators playing a crucial role.

Similarly, the Health Survey for England (1999) showed the highest diabetes prevalence rates among Bangladeshis (10.6%), although the other South Asian groups also showed high rates (Pakistanis 8.7%, Indians 7.7%). The highest age-standardised rates of diabetes were found among South Asian men and women: in particular Pakistanis and Bangladeshis of both sexes showed rates over five times higher than the general population. Indian men and women were almost three times as likely as the general population to report diabetes. With reference to the Gujarati population in general, Warrier (1994) confirms the difficulty in establishing exact populations, and similarly figures specifically for diabetes in Gujarati groups are difficult to obtain. However focused studies, such as that carried out by Simmons et al (1992) in Coventry, show Gujaratis to have prevalence rates of 8.4% and 8.8% (males and females respectively), this however does not indicate a national prevalence.

In terms of the kinds of methods used to generate this level of discourse, the focus has been on epidemiological, quantitative knowledge with some studies incorporating socio-economic factors in their analysis. The UKPDS (United Kingdom Prospective Diabetes Study) study, a twenty year clinical trial involving over five thousand patients, generated seventy-six articles in the twenty year period, all of which related to the clinical arena. Two of these involved ‘ethnicity’ as a factor of analysis comparing glycaemic control (Davis et al 2001) and cardiovascular incidence (UKPDS group 1998). Given that this was a clinical trial, it is not surprising that there was a lack of research into the experience of diabetes and the interaction between ethnicity and wider issues related to culture, and identity.
1.3 CONSTRUCTING THE ‘SOUTH ASIAN DIABETIC RISK’ - ETHNIC PREDISPOSITIONS?

As we have seen above, diabetes is a feature of the South Asian population both in the UK and in India. North American research has carried out in-depth research into the interaction between the environment and ethnic predisposition to type 2 diabetes (Abate & Chandalia 2003). This hugely complex picture involves processes of urbanisation and westernisation processes, and their effects on particular ethnic groupings. For example, in rural areas of India, there is a diabetes prevalence of 2%. In urban areas this increases to 8%. Similarly, for those who have migrated to Europe or other so-called ‘westernised’ countries, the prevalence again increases to 4 times higher than those in India (Dowse et al., 1990; McKeigue et al 1989). This impact of global human movement occurs across many different ethnic groupings as Abate and Chandalia (2003) show, but there is also another issue; different groups may appear to have different pre-dispositions when faced with similar environments. The public health implications are huge if certain groups of people are more susceptible than others to diabetes.

1.3.1 Lifestyle, diet and activity

Within the debate concerning diabetes prevalence and ethnicity, there are a number of well documented lines along which the arguments progress. ‘Lifestyle’ factors such as diet and exercise are regularly proposed as important elements of the argument, especially when linked to ideas surrounding the ‘acculturation’ process. Dietary forms in societies in the West are often said to be characterised by lowered fibre, increased animal fats and processed foods, and these have been associated with a higher predisposition to diabetes, through higher obesity levels (Hu et al 2001). Consumption of fats and refined carbohydrates are also factors in increased predisposition to obesity and type 2 diabetes – the risk of diabetes increases by 4.5 times for every 1 kg of weight gain. This in turn is related to reduced levels of physical activity, also associated with the ‘westernisation’ hypothesis (Manson et al
Studies in the US have consistently shown that the diets of migrants have over time and generations changed to include more fat, sodium, sugar and calories, but there does need to be vigilance in this issue. Gupta et al’s study (1995) implied that South Asians could be seen as a genetically distinct group – a race - who used too much “ghee” (clarified butter) for cooking and experienced a consistent lack of exercise – all of which have been refuted by other theorists (Abate and Chandalia 2003).

Research which examines the interaction of ‘ethnicity’ and diet do not seem to produce a strong argument. Schonfield et al’s (1987) study comparing Asian Indian men and European men – both vegetarian – showed the Indians to have increased insulin resistance, despite having identical nutritional intake, yet other studies have shown that diet alone did not contribute to insulin resistance (Sevak et al 1994). When one considers the *traditional* diet of many South Asians (especially Hindu Gujaratis) - vegetables, pulses and rice – it is difficult to imagine the ‘dietary composition’ argument holding any ground as an explanatory factor for high diabetes levels. In fact, as McKeigue et al (1989) and Matheson et al (1985) demonstrate, the South Asian diet actually forms a protection against some conditions such as colo-rectal cancer. The misinformation regarding the supposed unhealthy diet may well be a historical remnant of the health campaigns for the increased rickets syndrome in the South Asian community during the last three decades (Rocheron 1988) or the incorrect assumption in research and health education materials that fat content is too high in these diets (Bhatt & Dickinson 1992; Silman et al 1985).

Exercise and activity have also been at the forefront of both explanations and interventions for diabetes sufferers. The health intervention aspects of promoting exercise and activity for people with the disease is based on strong medical and biological evidence (Rubin 2001) - all of which demonstrate that exercise functions to control weight and improve insulin resistance. However, the ideas linked to various ethnic groupings lacking activity and exercise are spurious and foster a culture of blame rather than sensitive health care – much like the ‘culturalist’ explanations.
utilised in the late 1980’s and early 1990’s shown to be flawed, and which ‘pathologised’ (Ahmad 1993) minority health issues.

Although sedentary lifestyles have been associated with generalised obesity in urban environments, McKeigue et al (1992) show that actually it is not the lack of activity in general, or work activity, but the lack of leisure time activity which decreased (associated with health and fitness activity programmes) in Asian Indians in the UK. This seems to echo Ahmad’s (1993) vehement argument against pathologising ‘culture’ and ‘ethnicity’, and seeking a more socio-politically based explanation which accounts for inequalities in health status based in socio-economic positions. The lifestyle explanation therefore does not explain the high levels of insulin resistance.

1.3.2 The ‘Thrifty Gene’: Genetic arguments, diabetes and ethnicity

As a powerful correlate in studies of cardio-vascular diseases and diabetes in general, obesity is often used as a catch all explanatory term, so much so that a new term has been introduced into the literature – diabesity (Shafrir 1996). Biologically, obesity has been linked to the development of insulin resistance. The development of type 2 diabetes begins with glucose tolerance impairment, which gradually develops into the ‘metabolic syndrome’, a cluster of risk factors, of which one of the most important is obesity (Zimmet & Thomas 2003).

However, more recent arguments surrounding this issue with relevance to ethnicity and in particular South Asians, is the way in which fat is distributed around the body. Abdominal, truncal, or central obesity, has been shown in higher number of certain ethnic groupings than others (Gilbert et al. 1992). Asian Indians reportedly have higher waist to hip ratios and thicker skin folds compared to Europeans with comparable body mass indexes (McKeigue et al 1991). However, again the evidence does not have a strong basis to actually explain the cause of the illness. Abate and Chandalia (2001) showed that in a controlled trial, when compared with Caucasians
neither obesity nor fat distribution could explain high insulin resistance and type 2 diabetes in their group.

Genetic mutations of insulin receptors have been reported although are known to be infrequently occurring. The ‘thrifty gene’ hypothesis (Neel 1964, cited in Ferreira and Lang 2006) postulates that insulin resistance may have developed during periods of food deprivation by reducing the utilisation of glucose by muscles, and favouring other organs to use the glucose instead, such as the brain. When food suddenly becomes available and a sedentary lifestyle lowers the amount of physical activity, a pathological decrease in the utilisation of glucose occurs. The generally accepted model explains that the adoption of a sedentary lifestyle and high calorific intake has resulted in an obesity epidemic, and the related type 2 diabetes prevalence rates. However, as Scheper-Hughes (2006) argues, given there is no evidence for this gene yet, this is an example of bad anthropology combined with bad genetics. It simplifies or ignores the bio-social, socio-economic and political interactions that take place, and results in people being blamed for their illnesses.

Abate and Chandalia (2003) essentially argue for a primary metabolic defect – a genetic predisposition which when interacting with the environment, causes a much higher type 2 diabetes prevalence rate. This is further supported by Zimmet and Thomas (2003). Care needs to be taken here not to rest on the genetic argument of predisposition to insulin resistance, or ‘central obesity’ caused by the ‘thrifty gene’ – lest we succumb to the racialised discourse we intend to avoid.

Other factors such as stresses of various kinds have been known to be associated with prevalence of type 2 diabetes (Mooy et al 2000). Migration and the related exposure to different cultural, social, political and linguistic factors may cause inordinate amounts of stress. The South Asian population in the UK has been the subject of many studies which highlight the cross cultural problems of living in a host country in problematic climates (Ballard 1994). Such theories propose either that the migration has such a stressful effect on the migrant that their health is effected, or that the
natural selection involved in voluntary migration entails a ‘healthy migrant’ factor. Neither of these is sufficient in explaining the process of health status negotiation, and this is one of the major themes explored in the current thesis.

It is possible to argue that health sciences discourse has constructed what can be termed a ‘South Asian diabetic risk’, through a variety of ideas, including genetic predisposition to insulin resistance (McKeigue et al 1991); primary metabolic effects (Abate & Chandalia 2003; Zimmet and Thomas 2003) and so called ‘lifestyle’ and ‘cultural factors’ such as sedentary lives and inappropriate nutrition (Gupta et al 1995; BHF 2001; Naeem 2003). Hill (2006) re-problematises South Asian ‘cultures’, by making generalised claims about South Asian diets lacking in fruit and vegetables, and lifestyles lacking in exercise. While alerting us to the need for sensitive and specific diabetes healthcare, this seems to invoke the ‘cultural pathology’ notions of the past. The epidemiology of diabetes is not in question, but placing the burden of responsibility on “...aspects of South Asian culture” (Hill 2006: 64) needs to be taken with caution, as this offers little of theoretical or practical value, and increases the prevalence of stereotypes and caricatures. The explanatory utility of these various approaches is questionable. Through these discourses, there is a particular risk identity being shaped, which is informed by research treating ‘ethnicity’ and ‘culture’ as fixed and static entities.

1.3.3 Policy contributions to ethnicity and diabetes

This form of reification is not limited to research but also occurs in government initiatives limited in their efficacy in treating the concepts of ethnicity and culture. In a research review the Department of Health and Medical Research Council attempted to address the rise in diabetes cases in minority communities. The recommended method was implementation of “Innovative lifestyle educational methods...” which “involve working with Indian restaurants to provide low fat alternatives on their menus” (2002:129). Reducing the amount of unhealthy fats consumed by people may well have a biological and public health logic behind it, but the theoretical and
practical purchase of this needs to be questioned. The impact of health campaigns which target groups identified by a marker of difference based on unpacked concepts may range from immediate concrete stereotypes influencing health care provision, to long term systemic and institutional issues (this is represented in Patel’s (1993) account of racism occurring at different levels in healthcare). One would need to question the value of using low fat menus in Indian restaurants to combat the diabetes issue in South Asian communities, with specific reference to the target audience. The question needs to be asked: is there a group of mature onset diabetes sufferers who regularly visit Indian restaurants, and if so would having a low fat menu make a difference to the overall incidence and prevalence rates?

In addition of course there is a broader issue of the label “Indian restaurants”, given the view that this is not a homogenous group and is as internally disparate and distinct as the term South Asian. It is unclear how this strategy might impact the experience of diabetes management and health maintenance of South Asian type 2 diabetics. Embedded within this line of reasoning is the assumption that there is something ‘faulty’ within the ‘South Asian diet which requires a ‘fix’ of some sort, reverting health analysis to the older models of ‘cultural pathology’. Though health promotion has been under the watchful critique of sociology (Bunton et al 1995), as has health promotion for ethnic minorities (Bhopal and White 1993) there is a persistent production of discourse which reinforces simplistic notions of minority culture.

Related to this policy level action is the work of organisations which manage and coordinate support networks for people with diabetes. Diabetes UK is a national network for advice, support, information and health promotion activities. It has gained a prominent position in the field, both in terms of its profile in the lives of people who have diabetes but also as a conduit for biomedical research, and provides multi-lingual information to a number of ethnic groupings. However in a 2003 on-line publication which provided guidance on ‘cultural sensitivity’, we are told that “Hindus and Sikhs believe in reincarnation – as a result, many believe that their suffering from health-related causes is ‘paying for sins that may have taken place in their previous life’.
Many refuse to take medication because they see health conditions as 'an act of God' that is written in their destiny. Similarly many people from the Afro-Caribbean communities are highly superstitious and see 'having health conditions as a curse' (Diabetes UK 2003). Regardless of the intention here – which ostensibly is to provide some form of information about the diversity in people's belief systems which may impact on their health, the impact on health providers and clients is potentially problematic. Black and Minority Ethnic (BME) communities are constructed as somehow primitive and basic in their abilities to negotiate complex social, physical and emotional landscapes, and through homogenising internally diverse groups, are rendered helpless due to strict religion, faith, or superstition. Clearly, there is room for a more sophisticated approach.

The condemnation of such rigid and static use of categories of difference has also been echoed by Nazroo (1997), who additionally draws attention to what he calls “un-theorised ethnicity” through the use of epidemiological approaches (1997: 712). Here the issue is the use of ‘ethnicity’ without theoretical consideration of impacts or significance - especially for those groups of people who are objectified by the term.

This contributes to what can be identified as a series of frameworks which intend to not only explain diabetes in South Asian people, but simultaneously prescribe ‘fixes’ so that both the faulty genetic component can be dealt with, and the troublesome cultural traits (nutritional deficit, lack of exercise) can be dealt with adequately.

1.4 ETHNICITY, CULTURE AND HEALTH – SOME CONSIDERATIONS

Having discussed a variety of relevant factors associated with diabetes in South Asian groups, it is possible to say that there is a discourse that has been constructed in order to both describe and explain this phenomenon. The epidemiological models offer statistics indicating rates of illness, while genetic theorists combine their arguments with so called ‘culture’ arguments in order to explain these rates of the illness. As already demonstrated, many of these arguments have been questioned. However the
questions still at large pertaining to this study remain – what is the role of ethnicity and culture in the lived experience of diabetes? Do people within these groups accept these constructions of their identity as passive and non-concordant? Before this is dealt with, there is still the question regarding how the notions of difference, via the concepts of ethnicity and culture have been treated within research and literature. As Alexander aptly argues, there is no place for ‘culturalist heat-and-serve’ explanations (2004: 147).

1.4.1 Categories and labels

Smaje (1995) in a comprehensive review of the relationship between health, ‘race’ and ethnicity provided an insightful empirical basis to work with. Essentially defining ethnicity, race and their connection to people’s health status, the explanatory framework echoed a number of points made by the Black report (Black 1980), which stipulated that inequalities in health were created because of a combination of material, cultural and artefact factors. Smaje extended this by deconstructing ideas of ‘race’ and arguing that in its unproblematic usage, ‘race’ is an ‘ideological’ category, imbued with socio-political and historical constructions, while when ‘race’ is used as an ‘analytical’ category, it provides useful information about how people in various groups are faring in terms of health status – including experiences of health and illness, and access to health care. As Sheldon and Parker (1992) observe, often the mere description of ethnic differences evolves into an explanation of these differences – rooted in ethnic and cultural practices. One of the conclusions from many authors in this field, including Smaje (1995, 1996), Ahmad (1993) and Nazroo (2002), is that experiences of health and illness cannot be separated from the socio-political arena, and the combination of cultural and material environments people are in.

The simplistic use of culture and ethnicity as static and unchanging ideas has been vigorously critiqued (Ahmad 1993; Smaje 1995; Bhopal 1997). As reified markers of difference they can lead to what Ahmad (1993) has suggested is a loss of fluidity and dynamicism. There is also the resultant loss of explanatory power in research, caused
by rigid notions of what it means to belong to a specific cultural and / or ethnic grouping and the assumed related behavioural mechanisms involved (Kelleher 1996). There is a need to credit individuals and groups of people in society with agency, with the specific need in health and illness for elaborating how people demonstrate their agency and its relationship with other social forces. This issue is addressed by tackling the need for a socio-cultural and historical context to ideas about health and illness specific to diabetes.

Studies which do not reify culture and ethnicity but instead ‘reanimate’ static ideas of identity are increasing, although the initial momentum which occurred during the 1990s in terms of empirical, analytical and theoretical progress seems to have decreased. During this decade commentators such as Ahmad (1993, 1996), Hall (1992), Stubbs (1993), Nazroo (1997), Nazroo and Karlsen (2002), Smaje (1995, 2002), Lambert and Sevak (1996) and Kelleher (1994, 1996) made significant contributions to the study of health and ethnicity, through empirical findings and their theoretical location. It is within the arena set by many of these renderings of the health and identity relationship that this study sits.

1.4.2  ‘Cultural difference’

The relevance of ‘cultural difference’ as a concept is examined in Lambert and Sevak’s study (1996) of three South Asian groups in London, looking at perceptions of health and illness. They used structured and unstructured interviews to elicit information about eating patterns, climate and physical activity, psycho-social stresses; control and responsibility (echoing the general pattern for diabetes patients); constitution and heredity; and medical treatment. Although Lambert and Sevak’s study focused on coronary heart disease (CHD), the themes described above have important resonance for this study as climate and physical activity, and psycho-social stressors are both centrally located in the research findings. The importance lies in the authors questioning the tendency of researchers to accept the ‘common sense’ assumption of their being an essential cultural difference which affects health status.
‘Culture’ is often understood as a static entity – encompassing many different aspects of identity including religion, faith, language, ethnicity and class. The health professions in the UK which intend to research communities where prevalence and burden may be high but understanding still lacking, can assume that health behaviour and health status may be determined by something called ‘culture’ – as yet unverifiable. As Lambert and Sevak argue, “culture is made as much as given” (1996: 149) pointing to the conceptual fluidity which takes into consideration new circumstances, life events, observations and information.

South Asian culture - however it may be defined by ‘external’ sources - is often blamed or held partially responsible for illness and disease in these communities without substantial or theoretically robust evidence. As discussed earlier South Asian ‘culture’ is far too quickly paraded as the responsible charge for many diseases and ailments (coronary heart disease, diabetes, rickets, and obesity). Indeed, as Lambert and Sevak note, in terms of vulnerability to CHD, health messages, and behavioural change, there are striking similarities between White British and South Asian British people talking about their health experiences, leading one to conclude that the clumsy use of ‘culture’ to explain illness within a specific group, simply is not robust enough.

One important consideration which has crucial bearing on the current thesis is that of researching ‘culture’ and ethnicity on a specific disease basis. Lambert and Sevak warn against:

“isolated observations...about particular health problems...Without reference to the broader, often non-health specific, cultural constructs, social determinants and individual histories in which...(lay) ideas are embedded...” (1996: 153).

This study addresses this issue directly by tackling this need for a socio-cultural and historical context to people’s ideas about health and illness specific to diabetes. This has been accomplished by raising questions about migration histories, the associated
experiences people have and the consequences of this on their lives. As a consequence of this, the focus remains on the experiences of diabetes, contextualised by the socio-cultural backdrop of people's everyday lives. In addition there is also a requirement that the methodological base which underpins this is appropriately situated in critical ideas of ‘difference’ and culture.

Framing diabetes as a vehicle to explore how facets of people’s cultural and ethnic identity are used to actively negotiate a landscape may fill in the gaps left by much previous research. Some of the more sophisticated studies have indicated that there is a universe of meaning to be examined in looking at the social and cultural experiences of illness (Kelleher 1996; Lambert and Sevak 1996). This context points towards there being an active and dynamic element in the resulting accounts people produce. This suggests that rather than the constructions of passivity, and pathologised culture systems talked about in both research and policy, there is a different story emerging. That story indicates that people utilise their migration biographies, life experiences, their ‘designs for living’ (Becker 1986). Their notions of being Gujarati, Hindu, British, their connections to overseas and their ways of finding remedies in different systems to deal with and cope with their illness were part of these designs for living.

There are some key questions which will inform this thesis, and answers to which will elucidate the contributions made thus far to the debate concerning health and ethnicity: How is ‘difference’ characterised? How can health and illness experiences be linked to notions of ethnic and cultural identity? And in what ways have these questions been treated in the sociological literature?

Ahmad warned against the tendency for the ideological basis of ‘culture’ to be used in a form which when “stripped of its dynamic, economic, gender and historical context...becomes mechanistic, and determines peoples lives – actions and behaviours, instead of being a flexible resource for living, according meaning to what one feels and experiences” (1996: 190). Using concepts of ‘cultural difference’ as a way of explaining facets of social experience – such as inequalities – effectively is a
diversion away from structural inequalities and racism in peoples lives. The focus on the entity called ‘culture’ – usually a loosely and/or ill defined idea at best – employs taken for granted assumptions in research due to a racialised agenda. This is specially the case in the dominant epidemiological approaches that purport to be value free and objective. As Ahmad points out, black and minority ethnic communities are expected to structure their needs to suit health care professionals – rather than the other way round. As Sheldon and Parker (1992) argue health care professionals have a need to look at the way in which racialisation has determined the social, economic and epidemiological location of people.

The way in which difference is characterised, treated and then used in research is of course principally an ontological question. Planning, conceptualisation, outcomes and interventions will necessarily result in a concordance between this ontology and the nature of difference. That is, if the very conceptualisation of what difference means – for example defining South Asian people’s beliefs about diabetes and notions of inevitability – is categorised as a culturally fixed set of relations, then findings from research which uses these notions will most likely reveal fixed states of being and identity, no doubt suggesting that these ‘cultural’ findings point to this group of people being hindered by their ‘culture’. Although there is an established research base highlighting examples of cultural pathologisation and racialising health there is a persistent lingering of these static ideas. The ease with which fixed, rigid and static characterisations of people are used, acts as an incentive – a conceptual ‘one-stop-shop’. The current study aims to contribute to the slowly growing body of research which questions this trend, and points towards the direction of a theoretically informed, processual and contextualised account.

1.4.3 Difference, health and the political backdrop

The wider political and ideological debates regarding ‘difference’, race, ethnicity and culture are of course pertinent to this study, since the intention is to follow a narrative and social action thread from the individual’s story of diabetes, through their
connections with other people, places and institutions. Weaved into this account is also the connection the person makes with accounts of their own history – migration and settlement, education, work and positive and negative experiences in the UK – all acting as contexts and ‘buffers’ which mediate their health and illness states. This is a plausible telling of the micro-macro interactional relationship, as manifested in the structure-agency dialectic, which in turn is necessarily bound up in the political contexts of identity.

‘Pathologising culture’ rests on the shift from overt racism based on blood purity and genetic types to ‘cultural’ differences. The sense of essentialism remains the same, since minority groups are constructed as dangerous to themselves and can only be saved by becoming more like another group – perhaps the indigenous majority. The problem of course is that the ‘answer’ to ill health lies in minority ethnic communities listening to and following the advice given by health care providers, whilst the providers themselves are armed with an array of ‘cultural tools’ which allegedly will bring about sensitivity (working on the assumption that a little sensitivity can solve problems of a deeper, wider ideological, socio-political and economic nature). Such sensitivity has been the focus of interesting research, for example Hilton et al’s (2001) study on the traditional health practices of South Asian women in Canada, confirming that traditional practices were not used at the exclusion of medical remedies, and that health providers needed to be more culturally sensitive. The issue of course is that in being ‘culturally’ sensitive, what are the issues being acknowledged, and is there recognition of the full range of socio-economic, political and biographical arena that people actually operate in on an everyday basis?

It is not possible to discuss ethnicity and culture, and their interaction with health and illness without considering the embedded-ness of people in historical power relations. Sivanandan (1991) talks of the state shifting its emphasis in discourse from structure, power and racism to ideas of culture, ethnicity and difference. The 1950’s and 1960’s heralded a unity among UK “Black” populations (a political label given to many different groups in Britain at the time struggling to gain acknowledgement of the
racism and prejudice experienced), but this unity was seen as a threat. The state disunited this unity, and minority groups were split and disaggregated. Groups and people became 'ethnically distinct' as before they were 'politically common'. Communities developed 'day centres' and 'special projects', all organised around the notion of distinctive and culturally cohesive communities. Of course this political 'unity' amongst people from a huge and varied range of backgrounds could not live up to the idealisation it connoted – as Ahmad (1993, 1996) criticises – it was a fiction, since people were already split and divided according to differences other than 'race'. This wider political point has a relevance to this study, since it explores people's experiences not only of the individual and personal illness, but the wider landscape in terms of connections to community centres, temples, foci of religious and cultural events and dialogue. While critics of this “multicultural orthodoxy” point to what Sivanandan calls the commoditisation of cultures (1991), it is these very same units of identity, and locations of religious, cultural and social interaction which perform highly important functions for mediating peoples' needs. It overlooks the efficacy of those provisions at the smaller, localised and individual level (a point shared by Kelleher 1996) which are a result of local projects and large groups of disadvantaged people rely on them for power, voice and help.

Placing the health and illness states of individuals within the context of a political backdrop provides a wider debate for this study of diabetes experiences. For theorists such as Ahmad (1996) it is impossible to predict the behaviour of an ethnic group on the basis of cultural knowledge, country of origin or language since there are too many complexities involved. This “crude multi-culturalism” splits groups of people into identifiable chunks for ease of access, and theorists such as Ahmad (1996) debate the value of multiculturalism when placed against the political power of anti-racism. Anti-racism with its roots in the political unity of groups was able to mobilise and protest against racism – overt and covert and formed the opposition in terms of major debates of difference. As Brah (1992) summarises when she writes about the process of 'Ethnicism'– defining experiences in 'culturalist' terms, results in ethnic difference as the main entity around which social life is experienced. So called 'cultural needs'
are then defined independently of racism, gender and sexuality. Wider systems of oppression are effectively masked.

However, “crude antiracism” (Ahmad 1996) is equally ineffective in its ability to generate insights, since it may look at socio-political contexts at the expense of the ‘micro’ interactions people are involved in. Black and minority ethnic people run the risk of becoming the effect of racism, and the product of racism, rather than the producers and generators of social action which involves old and new forms of identity. Culture is flexible, contested, and shaped by social and structural contexts, generating cultural norms which are flexible guidelines within which behaviour is negotiated.

This study exploring the experiences of type 2 diabetes among Hindu Gujaratis in several communities in England takes as its theoretical stance a critical viewpoint, so that the concepts of difference that are recognised and identified are the substance of enquiry, rather than variables that once labelled can be categorised and used to describe or predict behaviour. In order to do this the study is also informed by constructionist and interactionist approaches which take into account more dualistic renderings of social action.

1.5 THE LAY EXPERIENCE - RELEVANT IDEAS IN CHRONIC HEALTH AND ILLNESS

1.5.1 Lay health experiences – beliefs or accounts?

The wide ranging research into what has come to be known as ‘lay’ experiences (Calnan 1987; Lawton 2003) of health and illness are extensive and diverse, dealing with class and socio-economic contexts (d’Houtard and Field 1984; Popay et al 1998), a variety of chronic illnesses (Bury 1982; Williams 1984; Anderson and Bury 1988) and gender (Blaxter 1983), to name a small number. Given that the lay experience is important to this study, this section reviews a number of noteworthy studies. Their
relevance stems from the research questions in this study focusing on people who are not technical experts within the medical or diabetes field, and yet who co-produce experiential health and illness accounts which are embedded in social contexts.

Lay ideas have been deemed central to our understanding of the social positioning and embedded-ness of health and illness states, and point us in the direction of context-recognising explanations for social phenomena. Where once non-medical citizens were simply ‘wrong’ if their ideas were different from the professional arena’s ideas, lay health ideas were given legitimacy. Prior (2003) discusses the legitimation crises in the professions as resulting in more partnership with citizens regarding medical health care, while Turner (2001) points to changes in knowledge status and ownership. As established convention in this field indicates, lay ideas are not simply watered down versions of medical knowledge, but rather shaped, structured and influenced by biographies and histories.

If lay ideas are as Lambert and Sevak (1996) suggest, embedded within cultural constructs and individual histories, then there is a conceptual and empirical need for a more nuanced recognition of what these cultural and social contexts are, when played out along side biographical experiences. A straightforward rendering of an account as a lay account is therefore not sufficient for the purposes of this research.

As Prior (2003) argues there is a wealth of information lay people have about their bodies. However, these knowledge frameworks are about their experiences of the condition and the impact of pain and disruption on their lives. But they are rarely professionals with a competency in technical medical arenas, and for this reason Prior (2003) warns against the use of the term ‘lay expert’. Though this sounds like a blow to the lay health frameworks important in the sociology of health and illness, I support this vigilance, for two reasons. First, there are semantic, conceptual and practical implications of being an ‘expert’ and these are the markers that differentiate one from having a lay role. Secondly, to use the term lay expert is to invite the objective / subjective dichotomy, and is too easily transposed to the ‘correct / incorrect’ equation.
Before plunging into research which titles itself ‘Lay experiences’, researchers could perhaps ask an important question about whether this research would look different if the word ‘lay’ was removed. This suggests a move away from semantic divisions between lay and non-lay, and focus on the generation of experiential, social context embedded accounts.

This echoes Shaw’s (2001) call to move away from the focus on lay health ‘beliefs’ and concentrate more on the accounts people produce – a point echoing earlier suggestions by Radley and Billig (1996). As Prior states, people are “expertly experiential” but we should not confuse the two separate areas of technical medical expertise and lay participation and consultation in medical matters (2003: 54).

In addition, certainly in terms of practical and policy implications of diabetes health care provision and partnership there are concerns about the role of lay ideas in the issue of lay-led self management (LLSM) programmes. Newbould et al (2006) indicate that caution should be taken in overstating the case for these initiatives, because of their as yet unproved efficacy, and perhaps more importantly for this study, the wide variation of experiences which chronic illness sufferers have, making prescriptive self-management initiatives a problematic endeavour.

1.5.2 The role of biography

As Lawton (2003) emphasises, in the last 25 years there have been a number of studies which have changed the way illness is regarded by those who study it. Among these are Bury’s ‘biographical disruption’ (1983); Charmaz’s ideas of ‘loss of self’ (1983); and Williams concept of ‘narrative reconstruction’ (1984). These are included here to provide some key ideas which help to inform this study.

Bury’s main thesis of biographical disruption focuses on the way that an illness can be a major disruption in life – drawing on Giddens’ work to articulate the critical nature of the disruption. The ontological ‘tear’ which occurs during a chronic illness causes a
crucial shift in a person’s biography and self concept. The multi-layered nature of this shift leads to a sophisticated re-appraisal of one’s life trajectory, psychological, emotional and physical / material. The relevance of this ‘disruption’ focused schema to this study is obvious – the onset of later diagnosed diabetes (type 2) can have a major effect on the individual with the illness, and effect many aspects of their daily operation. However, while such ontological ruptures and vicissitudes are part and parcel of many chronic illness experiences, the diabetic individual may well experience effects of a different nature. Type 2 diabetes is a disease which although carries many serious psycho-social impacts, is also a condition which can be managed with great success (as is the case with insulin dependent diabetes or type 1).

As critiqued by Williams (2000), although the notion of biographical disruption still holds conceptual value, there may well be issues surrounding its value at the empirical level. The notion of disruption does not for example acknowledge conditions which one has from birth, and which are part of the individual’s biography itself. As Williams argues, continuity rather than disruption is more a relevant characteristic here. There is also a class and privilege related issue here – illustrated in Cornwell’s (1984) study. A disruption may be experienced only when one is in the position to experience it. A more likely scenario is the experience of what in Cornwell’s study was called ‘normal’ crises. What some people may observe as disrupting, others may be able to blend into their everyday life. Having made these points, given that type 2 diabetes is generally a mature onset condition, the notion of having the continuity of one’s biography disrupted in some form still appears to be appropriate for informing the study.

Patients may mobilise resources, maintain relationships and activities, and as Rajaram asserts emphasising the role of stigma, through the process of “biographical reconstruction...strive(s) to maintain a positive sense of self...” (1997: 283). The resultant change in ‘self’ – the bedrock of interactionist ideas – is explored by Charmaz (1983), who focuses on the tendency for the chronically ill people in her study to lose a sense of ‘self’. Self images are seen to be gradually destroyed, without
any new, positive and valued ones taking their place. As Lawton (2003) summarises, Charmaz advances our understanding in two main ways. Firstly we are given a perspective of illness in an everyday context, rather than a narrow medical view, and secondly the multi-faceted nature of the illness is discussed – problems with self identity in one area lead to problems in other areas. The value of this ‘loss of self’ approach is substantial for approaching the way diabetic patients might view themselves, their illness and their life, in the context of the condition. As other aspects of their lives are also affected by the nutrition, medication, physical, symptomatic and social changes they experience, so we would also expect a change in identity. However, type 2 diabetics, as the literature indicates can be very adept at managing their condition and not succumbing to the regime of the illness.

Closely related to the above frameworks, Williams (1984) argues for what Lawton describes as partly a “continuation of the story where Bury and Charmaz left off” (2003: 26). Strategies used for creating order, coherence and stability are the focus of this work. Looking at long term effects of a particular illness, Williams examines the self concept of his participants. The core of the framework is the issue of how people will give a meaningful status to their illness in their accounts, and the ways in which narrative is used to reconstruct their lives with history, politics and morality. As Williams states, it is an attempt to re-establish the link between “body, self and world” (1984: 197) by connecting different aspects of biography. Again, here the relevance to this study is clear – we can usefully employ a framework which can examine these ruptures in the lives of sufferers, but also look at how narratives show us the re-building of a life. Utilising a wider relationship between the individual, society, and notions of chronic illness, Williams (1984) demonstrated that illness management is not just about attending to medical aspects. The management takes place in the context of societal circumstances, where certain moral judgements are made and traits such as control are valued. As illness represents some loss of this control, the management of the illness can be seen as a moral practice through which some virtue is maintained, and an identity linked to ‘health’ rather than ‘illness’ is re-enacted. This elaboration of a ‘morally laced’ enactment of illness management is a
useful conceptual tool, which facilitates a sensitive analysis of diabetes experiences in the context of everyday life and contributes something more to a picture of a socially contextual placement of culture.

The notion of lay ideas is of course important in this thesis, but not in the traditional sense of lay health “beliefs” – which suggests there are unmoving internal beliefs which the lay person imparts to the researcher (Nettleton 2006). Instead the experience of type 2 diabetes as located in everyday life, and its interactions with ideas of cultural and ethnic identity is focused upon, which invariably intersects with experiences had by lay people.

1.6 SPECIFIC APPROACHES TO THE DIABETES EXPERIENCE

The literature reviewed above has covered a wide range of topics concerned centrally with the ways in which lay ideas of health and illness might inform this study, and how a chronic illness such as type 2 diabetes – can disrupt a persons’ sense of self. In this study this refers to both the private and intimate self but also the social self.

The studies which have been critically reviewed are contributions to a number of overlapping areas – chronic illness, illness narratives and lay experiences of health and illness and many of the diabetes specific studies make use of these conceptual frameworks. These frameworks all contain elements - conceptual and methodological – which have a direct relevance to this study of type 2 diabetes.

1.6.1 Managing, coping, controlling

Campbell et al’s (2003) meta-ethnography resulted in a useful synthesis of qualitative research on lay experiences of diabetes. Their starting point was the classical study by Kelleher (1988), and went on to synthesise a number of other papers – useful for the purposes of this study to evaluate already extant work in the field. Campbell et al were able to discern six main concepts: responses to diabetes; control; health and well
being; experience and the need for knowledge; seriousness of diabetes and communication between patients and providers. One of the main themes to be explored in the current study of Hindu Gujaratis is ethnicity, cultural identity, migration experiences, and the intersection with health. Included in this is the use of traditional and herbal remedies which are explored in this study. Although there are a small number of studies which examine the use of these complementary remedies (e.g. Bhopal 1986; Wood et al 2004), they have not traditionally been the focus of much of the literature within the field.

Kelleher’s (1988) study can be summarised as one which establishes three types of responses to diabetes – ‘copers’, ‘normalisers’ and ‘worriers’. These categories are further echoed in Maclean’s research (1991), which aimed to achieve the broader goal of a holistic understanding of the diabetes experience by looking at adherence to diet regimes. Again, categories were established ranging on a continuum from strict to no adherence, which according to Campbell et al (2003) corresponded to Kelleher’s three category typology. All of these studies purport to investigate the broad sweep of ‘meaning’ manifested in the subjective experiences of diabetes. Included within these meanings is symptomalogy – again relevant here as it is part of the established literature and is an emergent finding in this study.

Control or lack of control in varying degrees, is a central theme in diabetes literature, as reflected in much of the research (Kelleher 1988; Maclean 1991) with a variety of corresponding and associated affective states. For example, people who feel they are in control of their illness usually feel positive about the condition, while those who feel “buffeted” (Maclean 1991: 694) by it had very negative feelings. Studies which look into this issue conclude that within the realms of the concept of control there are degrees of control, and related issues of ‘strategic cheating’. ‘Non-compliance’ – as it were – can come in a range of forms, and doing so in a thoughtful and strategic way has been manifested in many of the studies in this area.
A powerful theme and one which elicited interesting interview interactions, was the idea of familiarity. In the diabetes literature, this could be linked conceptually to ‘experience and the need for knowledge’ — and is inherently related to self care. While Maclean talks of wisdom gained from experience (1991) and Kelleher (1988) discusses how this experience was sometimes more valuable in its specificity than a doctors general knowledge, there is a lack of acknowledgement of what else this type of self care might entail. For example, familiarity does not need to stop at the persons’ own experience of the illness and the body, but could certainly be extended to other people in the family or social circle with similar experiences. Additionally, this type of reflexive knowledge is not necessarily limited to adherence to diet, but could also be employed in the trans-cultural and trans-global transferral of knowledge and remedies. Murphy and Kinmonth (1995) emphasise the lay health sociology message — that patients are not simply passive recipients of medical knowledge — but again this requires a more developed argument to render the picture of experience more fully.

Kelleher’s (1988) synthesis focuses on a small number of main issues: the experience of diabetes, living with diabetic treatments, compliance and non compliance, social relationships and issues surrounding the care of diabetics. The theme which binds these sections is essentially the ways in which a diabetic responds to the advent of the illness in their life, acquires knowledge about the illness and treatment, weighs up the costs and benefits of changing their life to cope with the illness, and adapts emotionally, socially, psychologically, and practically.

There are a variety of factors involved in a diabetic following a prescribed treatment path, or deviating from it. Kelleher (1988) consistently shows that the changes in lifestyle routine affects social relationships, working life, family patterns, and these can also be influenced by factors related to socio-economic status, whereby some sections of the population may have more access to financial resources and time flexibility in order to follow their daily treatment more rigorously. Diabetics may not fully understand the complex details of their illness, and the often complicated system of monitoring and evaluating the body’s state. As studies show, there are many factors
involved in the active and inactive evaluation that contributes to a decision, which involves a variety of prioritising measures. Kelleher discusses the many roles and responsibilities a person may have to operate within. It may be within the parameters of these roles and the duties they hold that a diabetic will set priorities according to their needs, and which results in a particular form of treatment adherence. While medical professionals may use the terms compliance and non-compliance, this may actually be the diabetic patient exercising individual choice based on personal life circumstances and the bringing to the medical encounter of their own agenda in addition to the medical agenda (Kelleher 1988).

1.6.2 Diabetes and socialities

Another of the central themes around which much of the diabetes research is focused is the social relationships involved in the diabetic life and experience. There are a variety of factors which play a role and which would easily be overlooked without sociological scrutiny. Again, Kelleher examines the ways in which the diabetics’ adjustment and coping within the context of social, psychological, practical and emotional issues surrounding the illness may somewhat be buffered by the relationships they have with the people around them in a variety of roles. These include parents, siblings, other family members, friends and helpers. The immense responsibility of self monitoring, administering injections and / or tablets, adherence to and control of a dietary routine, and the related constraints on life, may well be shared by people who have placed themselves within the radius of support, or who are there involuntarily (parents, siblings, close friend, health workers). However as Kelleher asserts, these supports and interventions are not always positive. Many times the diabetic is socialised into a sick role, where they are encouraged to accept the limitations imposed on them by the illness. This can have the effect of reminding the diabetic of the seriousness of the issue and result in strict adherence to the prescribed programme, or sometimes lead to an overstatement of fact and an unnecessary cautiousness. While the “family climate” provides a supportive backdrop, it is clear that Kelleher also discusses the problematic nature of the “double bind”. This appears
to be a consistent theme running through the literature on diabetes – the often conflicting ‘life worlds’ that a diabetic occupies.

This ‘conflictual life paradigm’ is demonstrated in the impact that stress can have on a diabetics’ life. The idea that life changes which may have implications in losing social relationships may have a corresponding effect on blood sugar level monitoring is also taken up by Kelleher, with reference to the other direction of the relationship – how diabetes affects social relationships.

As discussed earlier the idea of ‘lay’ experiences is important in all of these studies, and form a key construct in this area. Schoenberg et al’s (1998) work which focused on lay perspectives on the origin and management of type 2 diabetes among women concluded that there was a meaning-making process taking place in individual’s accounts, and participants were linking their current strategies of management with past practices and history. While their study does discuss the life experiences, knowledge repertoire and socio-economic contexts, this is done without any substantial reference or discussion of cultural identity, and the way examination of this relationship to health may contribute to the structure and agency debate. There is much focus on internal psychological processes, including the locus of control ideas (Rotter 1982). However the notion of ‘revisioning of explanatory models’ may have benefited from a closer look at Charmaz’s (1983) interactionist based work on chronic illness and identity for a more social context oriented account. In addition there was also a speculative expectation that African-Americans in the study would be using a specific culturally consistent illness construct which would have greater variance with the biomedical model than white counterparts. The findings which confound this expectation are explained as African-Americans having relatives who work in the health care system and media messages. There is however no theoretical or explanatory speculation or suggestion that these findings might be down to individuals making sophisticated and informed social and personal decisions about biomedical and alternative model use. These are inadequacies in the current research which this study hopes to address.
Although the problems in much diabetes social context research span methodological and conceptual issues (and therefore can have implications for service delivery and use), other studies have applied a critical gaze to this area by focusing on the understandings and meanings patients attach to diabetes service delivery (e.g. Lawton et al 2005). Again the emphasis rests on a need for reconceptualising the context in which patients receive care. This includes the place in which they are treated and advised, but also the “broader contours and features of patients’ everyday lives” (Lawton 2005: 1431). Here we are presented with research which presents a more nuanced picture of how people manage their condition, and how they perceive and negotiate care delivery in the context of their everyday lives. The drawback here however and one acknowledged by the authors - is that the participants were newly diagnosed, and therefore had experiences that are quite different to people more used to their condition. There is also a health care provision implication here – that providers may be presented with particular challenges with ‘long-termers’ (such as those in this study) who may not take fully acknowledge seriousness of the condition. This presents a problem if we are to gain an understanding about the embodiment of the diabetes experience – and something which is addressed in the study design within this thesis.

As the literature shows causality of diabetes is a constant theme in the exploration of diabetes experiences. However, simply probing ideas of perceived causes of diabetes is little guarantee of gaining social and cultural insights. Mercado-Martinez and Ramos-Herrera (2002), in research situated within the medical anthropological field argue that socio-emotional circumstances and life experience practice¹ are evident in lay people’s ideas of causality – mainly in terms of negative emotions causing diabetes. This however runs counter to Ferreira and Lang’s conclusions which argue for the protective function of “emotional liberty” (2006: 13). This in-depth ethnographic work of medical anthropology forms a milestone in this area, providing theoretical, methodological and empirical pathways for looking at diabetes, and also

¹ Factors which are not usually found in this arena of research (though cultural epidemiology has proved this area to be fruitful in both psychological and somatic conditions, see Weiss et al 2001.)
provides useful directions for this study to link with. Although Ferreira and Lang (2006) discuss many ways in which the individual with diabetes manages, copes, and negotiates social and cultural landscapes, there is a conspicuous absence of discussion about the agency and structure dialectic — their work sophisticatedly shows evidence of this analytical thread, but requires more explicit accounting.

As already suggested much of the discussion surrounding type 2 diabetes focuses on adherence to medicine, advice related to diet, nutrition, exercise, and glucose monitoring. However, there is a place in the type 2 research arena for more in-depth work to be done on precisely those aspects which involve ‘reconstructive social processes’, through narration and biography. The process of re-negotiating identity needs to be placed in the context of categories of difference. For example, how does a middle aged South Asian woman, who has been diagnosed with type 2 diabetes, who also suffers from symptoms of fatigue, pain, isolation, and language barriers, attend to her illness? What can that attendance tell us about how she conceptualises her ethnicity, and cultural identity? This may be placed within the context of socio-cultural milieu, so that factors such as her migration history, her networks with friends and family in India which may facilitate her contacts with complementary medicine and her social, cultural and religious connections in the UK, produce a more rounded and richer picture than simply a patient complying or not complying to medication regimes.

As already emphasised elsewhere in this chapter, it is the social and cultural milieu of the everyday life of a type 2 diabetic which affects and determines the management of the illness. The cultural lives of South Asian patients need to be elaborated. The religious and cultural location of their ideas of distress, causation, and resulting help seeking require far more attention than already demonstrated in the literature. The problems discussed in what can be called the ‘race’ literature (for want of a more appropriate label) have developed into sophisticated analyses of categories, labels, and processes of objectification. As Smaje (2000) proposes, sociological investigations necessarily need to provide a means to question ideology in relation to health, illness
and ethnicity. This means locating the concepts of race and ethnicity in a wider socio-historical context. We can extend this argument to the qualitative and in-depth sociological investigation of a chronic illness such as type 2 diabetes, and ensure that enough attention is paid to those aspects of a ‘diabetic’ experience, which may provide a more detailed and richer picture of that experience. This study does not take concepts of race, ethnicity or culture for granted, but rather ‘unpacks’ the meaning some of these concepts may have for our understanding, and the relevance they may have for the diabetic’s experience.

1.7 DIABETES, CULTURE AND ETHNICITY

The Gujarati section of the British South Asian population is comparatively under researched. Most research which has purported to examine issues related to health and ethnicity in the South Asian population bases its distinction between groups solely on national and intra-national boundaries — hence Indian, Pakistani and Bangladeshi groupings. However this is a gross oversimplification of a complex issue. The homogenising of groups which are clearly distinctive in terms of culture, language, social and community networks and migration histories does no justice to the experiences these people have. There is very little distinction given to varying organising principles such as caste, which as a global diasporic organisational and logistic phenomenon has very different manifestations according to the caste characteristics. Nor is there much distinction in the literature reviewed (Ballard 1994 is an exception) between British South Asians from India, and those who arrived in the UK from Africa – both groups who have had different socio-cultural experiences.

The literature on the experience of diabetes, seldom ventures into in-depth studies of minority groups, though the last decades have seen interesting development (e.g. Greenhalgh et al 1998, 2005; Ferreira and Lang 2006). This is in stark contrast to the traditional epidemiological studies based on data from a variety of population studies. A literature search confirms that in-depth qualitative research is lacking in this area, and while there is an abundance of studies which look at the experiences of White
people in the UK, again, in-depth research in the British South Asian communities is lacking (exceptions are Kelleher and Islam 1996; Greenhalgh et al 1998; Lawton et al 2005; 2006). This indicates that while the intersection of medical sociology and ethnicity has found some ground there is still an underlying assumption that the experiences of all groups are contained and reflected in the White group so often the subject of research. This has a profound impact on the service provision for BME communities around the country. The 2002 National Health Service Framework for Diabetes Care – Standards’ is a protocol setting out how to address the huge public health problem that diabetes potentially is, especially due to its inherent link with obesity and cardiovascular disease (NHS 2002). Within this document there are a handful of references to the ethnic minority community, and the need for research which undertakes this seriously. While vaguely indicating that certain ethnic groups in the UK are more susceptible to diabetes than others, the document does not explicitly entertain any concrete research proposals, or discuss just how serious the problem is. Neither is there any mention of a sociological or psychosocial approach to the examination or study of diabetes in BME groups. This is also supported by Choudhury et al (2003), who stated that the current ‘too little too late’ ethos is compounded by the national service framework’s neglect of these factors.

1.7.1 Diabetes and identity – action and reaction

The subtle analysis of political and individual personal worlds, as carried out by Kelleher and Islam (1996) has a strong point of identification for this study since his early seminal work in diabetes forms a basis for understanding the experiences of diabetics, and Kelleher’s (1996) later work also informs the impact of ethnicity and culture. By understanding how people respond to categories and labels applied to them externally, Kelleher’s studies on diabetes among a Bangladeshi community allow insights into how people can use notions of ethnicity and culture in flexible ways in order to manage their illness. This is carried out by using a variety of what Schutz (1966) has referred to as structures of relevance, which are facilities people have around them which enable them and empower them to function and interact. The
participants in that study were trying to manage their condition by remembering medical advice and making adjustments to their diet – but these changes had symbolic implications. The food they ate had links to their Bangladeshi and Muslim identities, and these were structures of relevance utilised to make sense of their condition in the context of their social and cultural lives.

Ethnicity then, for Kelleher is a structure of relevance used by people in a variety of ways in their everyday lives, and by analysing this it is possible to ascertain how differences between groups – the culturally different substance of multiculturalism – have a role in how people manage their situations. This seeming opposition to the more wider-looking anti-racist line argues that colour may not be the entity by which people want to be primarily categorised by, nor united by. For Kelleher, ethnicity is a non-essential and constructed entity, made as much by people themselves as others in the dynamics of power relations. In a similar viewpoint to Lambert and Sevak (1996), culture for Kelleher, is a “dynamic entity, which changes to incorporate fresh ideas and perspectives as people develop new ways to respond to their environment” (1996: 71).

The sophisticated way in which Kelleher draws upon sociological theory in order to explore identity through diabetes experiences is still relatively rare, although recent work examines this area and makes useful links with health care provision (Lawton et al 2005; Greenhalgh 2005), and these do provide some interesting viewpoints regarding the experience of type 2 diabetes among South Asians. Lawton et al (2005) for example report how the use of oral hypoglycaemic agents (OHAs) among Pakistani and Indian participants was mediated by a trust in the efficacy of British medical systems. Knowledge and experience of remedies from the Indian sub-continent also influenced the decision – something which has resonance with this study. The findings strike a chord with this study since the decisions that people made were about negotiating the condition in terms of the particular context they found themselves in – and so the ingestion of OHAs fluctuated depending on their needs and perceptions. Some of these factors were as Lawton et al argue ‘cultural’ as they were
related to their ethnic identity, and influences attached to this, such as knowledge and experience of remedies from the Indian sub-continent. This however is contested by Greenhalgh (2005) who, having also conducted extensive research into diabetes mainly among the Bangladeshi population in London, argues that this should not be seen as primarily a 'cultural difference' but rather 'human nature', and suggests the patient’s level of health literacy is more important than 'culture'. In terms of relevance for this thesis, this is important because the history of health and ethnicity research has demonstrated that often differences in health status between groups are put down to a vaguely defined notion of ‘culture’ (Rocheron 1988; Dominelli 1988; Ahmad 1993). However, Lawton et al’s research appears to be less simplistic than this, and offers a complex discussion of the relationship between health provider, diabetic patient, and the social landscape they are situated in.

Indeed, Greenhalgh’s work on ‘sharing stories’ included Gujarati speakers and the use of bi-lingual health advocates leading Gujarati groups in health education. The reason for the distinction is to avoid reifying and freezing identities as self-supporting structures, and the static categorisation of people into ‘either-or’ placements. Rather it is possible to make a statement about how labels and markers of difference do matter, because they can indicate important cultural and linguistic nuances, affecting the outcome of explorations. The notion of ‘sharing stories’ – a way of engaging with non-English speaking diabetics – through user groups and bi-lingual advocates can lead to “learning, empowerment and change” (2005: 632). However, within Greenhalgh’s work, not withstanding the crucial community engagement and user empowerment models it employs and seems to result in effectively, there persists somewhat a notion of professional validation seeking. That although South Asian people with type 2 diabetes are given an opportunity to share their concerns, this is still very much in the light of assessing ‘what’s gone wrong’ within people’s actions, or where deficits may occur, in either knowledge or action. While a step in an encouraging direction and certainly useful for user groups, it may still beg the question about what resources people have developed over their life-times, how they
fit and utilise their experiences into their management of their health status, and what this says about cultural identity.

As Ferreira and Lang (2006) have intensively and extensively demonstrated, it is possible to gain access to people’s cultural worlds, in the context of their history, their culture in symbolic and practical terms, and locate health ideas, solutions and avenues for better lives within the social and cultural lives they live. Hagey (1984) discusses incorporating cultural knowledge into health education in Toronto among the Aanishinaabe people, while Greenhalgh et al’s (1998) earlier work emphasised how beliefs in their Bangladeshi sample could be used effectively in culturally sensitive diabetes education.

Advancing the community empowerment model then, albeit with indigenous groups around the world, a variety of anthropologists have taken a socio-historical, political and culturally critical stance on how diabetes has been brought about. These models frame diabetes in terms of a series of historical and political forces which have brought about the decimation of traditional cultures through power relations and inequalities resulting in unequal access to a range of resources (Ferreira and Lang 2006). These processes include limitation of access to appropriate and culturally traditional food and diet resources (Lang 2006) and internalisation of the construction of a ‘genetic’ risk (Scheper-Hughes 2006). The approaches used are explicitly anthropological, and although there is no mention of sociological discussions of the relationship between agency and structure, these studies are particularly steeped in a combination of ethnographic anthropological work. These provide insights into the political and historical forces that impinge on what people do within the diabetes experience, how they do or do not manage their illness, and the kinds of socio-cultural contexts people operate within. These studies progress the area further by creating – with indigenous groups – programmes of health awareness which take as their focus their own history, life experiences, systems of traditional knowledge including herbs and foods (Korn and Ryser 2006).
As Ferreira and Lang (2006) vehemently argue in their ‘local knowledges’ and community empowerment thesis, accounting for the histories of people where oppression and subjugation have been central to people’s lives over generations is key to understanding not just ‘how’ questions in diabetes, but ‘why’ questions concerning diabetes in indigenous populations. Although the people in this study are not ‘indigenous’ and not perhaps strictly categorised as ‘oppressed’ (though this is infinitely debatable), there are some interesting possibilities in looking to narratives and life worlds within the diabetes experience which help to facilitate understanding of wider historical and discursive forces.

1.8 THEORETICAL PLACEMENT

As this study used a grounded theory framework the generation of the data and emergent findings were the driving mechanisms behind the types of theory that were deemed useful. However, this chapter has demonstrated that there were several theoretical strands or approaches which are particularly useful. The symbolic interactionist rendering of social action as a process of internal and external mechanisms and reflections, mediated by action and re-action is particularly useful, especially in examples such as the work of Kelleher (1996) and Nagel (1994). Schütz’s (1970) structures or zones of relevance, utilised as a theoretical foothold are pertinent to this study because of their intuitive and empirical value – in most of the diabetes experience studies there is evident to some extent people’s identification and use of various structures around them which they decide to use in accordance with their needs. The work of Reed (2003) which uses notions of syncrecy and dialectics to frame both the use of remedies and the dynamic nature of identity is relevant for its sophistication in acknowledging the lived social and cultural worlds people are located, and the placement therein of their health and illness states.

The major debates between multiculturalism and antiracism have had a major impact on how health and illness research has been conducted, since the epistemological and ontological basis of research effectively either include or exclude specific versions
and tellings of social reality. For this reason the theoretical debate on difference, race, ethnicity and culture has formed an ever present basis in this study. As Smaje (1996) has argued there is more need than ever to have explanatory power underpinned by social theory. Finding out what people do with their diabetes in the context of their lives – in the past and present using a situated methodology is a step towards this goal.

While the application of labels of difference can be an unbalanced power relation, it is also possible to see this as a two way process specifically drawing on the work of Nagel (1994), who applies the symbolic interactionist rendering to discuss the notion of ‘symbolic ethnicity’. This connects with other theorists who demonstrate that a group will also have its own role in defining itself in terms of its ethnic and cultural identity. This strategy is drawn upon heavily in this study, since through people’s accounts of what they do with their diabetes, who they connect with and how they see themselves in a social framework of living can tell us a great deal about how notions of identity are both stable and in flux. As Hall (1992) has argued, the idea of a single and fixed identity is a fantasy which simply serves to comfort us in the post modern era – the narrative of the self is a construction of the period we live in. Using this to inform this study of first generation South Asians, one needs to ask how do they perceive themselves? How do their experiences of their countries of birth, work and origin before the UK influence their decisions? How might a chronic condition such as type 2 diabetes be managed using these experiences? And what happens to prevalent constructions of South Asian minority groups when their experiences, perceptions and accounts are explored in situ?

Given that ethnic differences are constructed differences – by people themselves and the power structures around them which can and do operate on a racialised basis, people can play a substantial role in the process of constructing identities. Kelleher (1996) makes the point that though communities may be ‘imagined’ (Anderson 1991) and people are pulled many different ways by contradictory identities (Hall 1992) there are real consequences for people who use these communities in real ways. Again
the agency-structure duality is very much in force in this line of argument and forms a strong basis for this study. One of the major aims of this study was to characterise this agency and structure process, the dialectic of personal and public identity and what mediates it in the process of health and illness management. People are still not “cultural dopes” (Garfinkel 1984:68) and it is through the exploration of what they do in showing they are not being cultural dopes that insights might be gained.

The question which this discussion raises is how is the idea, or notion of ethnic and cultural identity used as a resource which helps people to deal with diabetes as a life-embedded fact? This study aims to show how concepts which academic research and health policy call “ethnicity” and “culture” are conceptualised and used by people in their everyday lives as they manage their illness and go about the daily business of their lives. What research and policy may understand as an ethnic or cultural entity is what people generally know to be ‘normal’ everyday life and its vicissitudes.

The above discussion illustrates how ethnicity has been treated within health discourse within the various socio-political debates regarding multiculturalism and anti-racism. While these debates flourished in the 1980s and 1990s, the new millennium has brought a wave of different, perhaps recycled challenges that need to be faced. With Giddens’ (1991) notions of the modern reflexive self still retaining its influence, and Bauman’s (2002) liquid modernity, alongside the intellectual purchase of Hall’s (1992) thoughts about post-modern identity having no fixed place, there is still a sense in which ideas of identity are nominally fluid, and yet in practice require fixing in order to apply and use them. The notion of fluidity and elasticity is easier to allocate to ethnicity and culture intellectually and abstractly, but when applying these concepts to people’s lived experiences of health and illness, the task becomes more difficult. This is evident in current debates on multiculturalism against the backdrop of reified concepts of difference.

However, an insightful and carefully thought out approach which is sensitive as well as robust is provided by Reed (2003) in her work on the health choices of South Asian
mothers in Leicester. Her work addresses the interconnectedness of vital sections of experience: ethnicity, women’s health, alternative health, identity and globalisation. Using Fitzpatrick’s (1984) idea of syncrecy – a generic term which has also been applied to discussions of ethnicity and identity is a free floating signature point in her work. Syncrecy as a phenomenon that can be dynamic, transformational, and the subject of processes which undergo constant and active change, holds a strong influence in her work as it is characterised by the social contextualising of experience.

Reed uses a dialectical approach to explore syncrecy and context in the health choices of women, allowing for, as she quotes from Schrijver (1993) ‘a plurality of views and a multi-vocal discourse’ (Reed 2003: 18). Although this multi-plurality of views is common place in qualitative health research – especially related to ethnicity, Reed’s approach goes beyond the standard approach, because it specifically addresses and explores both local and global processes and brings into the equation history. This element when combined with social context and analyses which take on board the subtle nuances of experience, make for an insightful argument. Acknowledging individual and group processes as being mediated by agency and structure, Reed’s work charts important links between among other factors - generation and the life course, religion and community, and location, space and globalisation. These are building blocks for mapping the conceptual, methodological and empirical territory that is needed in health and ethnicity research.

Reflecting this, the diabetic’s world is not a static, unchanging one, where a conscious choice is made about the direction or type of coping, or a particular route. This study aims to show that while there will be certain universal elements of the medical experience of the condition, there are as Reed has demonstrated, an entire range of social, cultural and historical contexts which will influence how the Gujarati diabetics in this study experience not only their illness, but the way in which the illness is situated in their life circumstance. Hence these ‘cultural negotiations in health and illness’ point to the involvement of the active and changing process of negotiation in coping and managing the illness. As reflected in Reed’s work, there may well be a
myriad of different influencing factors such as migration experiences, racism, socio-economic factors and experiences with traditional healing methods which will all have a part to play in the way in which a person experiences diabetes, and the meaning it has in their life.

Again the emphasis is on approaches which help to solve the problem of what people do personally and in the wider context; the question is not whether this relation exists of course, but rather what is this relation? Here the work of symbolic interactionism, already mentioned earlier in the work of Kelleher et al (1996) and Nagel (1994) may be of use. Meltzer et al neatly summarise the query: “The behaviour of men and women is caused not so much by the forces within themselves, or by external forces impinging upon them, but what lies in between, a reflective and socially derived interpretation of the internal and external stimuli that are present...the social origins of the self and human nature” (1975: 2). In examining what happens in the management of type 2 diabetes in this sample it now becomes useful to look at how people themselves might interpret their everyday actions in the immediate present as well as interpret their own sense of histories and experiences called upon in this everyday accomplishment.

This examination of how difference, ethnicity and culture and their relationship to health as mediated by notions of agency and structure is central to this study, for it traces the trajectory of social action, from individual to social collectivity, by examining a variety of mediating and buffering factors, such as migration history and life experience. Smaje (1996; 2000) and Spencer (2006) discuss the merits of the work of Pierre Bourdieu in looking at ethnicity and health revealing similarities and points which indicate a useful approach to the area for this study. These connections are developed as part of the further development of this area in chapter 8.

The common thread which holds these examples of research and literature together for the purpose of this study is that it enables us to locate experiences of diabetes in the social and cultural worlds which have always been the very *raison d'être* of sociology.
Epidemiology, social epidemiology, and early research into health and ethnicity provided versions of the relationship between health and ethnicity – all driven by ontological and epistemological roots. These however overlooked the ideological and socio-historical construction of symbolic markers of difference, the impact on people’s lives, and how people themselves are able to re-negotiate labels, borders and identities. This points to an examination and exploration of what people do with the resources they have around them – these resources being their own life experiences sourced in migration experiences, their work experiences, their knowledge systems, and their connections to people and institutions in and outside their immediate circle of social existence.

SUMMARY

This chapter has looked at the nature of diabetes, the epidemiological rates of the illness among various groups and more specifically South Asian groups in the UK. The explanations for high rates of diabetes that have been proposed have relevance for this study because they have a direct impact on people’s lives – both how they might come to see themselves and how health discourse regards these groups and the conceptualisation of any potential health intervention or collaborative programme. The explanations and ideas put forward have tended to concentrate on the genetic, lifestyle and cultural explanations, using static and simplistic notions of culture and difference. This literature has on the whole been debated and contested. I argue here that these combined arguments contribute to the construction of a ‘South Asian diabetes risk’ identity. Weaved into this thesis are notions of the lay experience of diabetes. Explorations of people’s accounts when situated within their social, cultural and personal contexts can tell us something useful about how ideas of cultural identity are invoked and implemented.

Given the discussion regarding useful empirical and theoretical approaches that have made a contribution to understanding the experiences of black and minority health experiences, this study explores the following research questions:
• What is the experience of having type 2 diabetes among Hindu Gujaratis?
• How do Hindu Gujaratis manage their diabetes and what types of mechanisms do they draw on?
• How do notions of culture and identity impact upon their experience?

The following chapter presents the Methodology used in this study to generate the sample, the findings and the emergent theoretical arguments proposed. It also provides a situated backdrop to the research process, the role of the researcher’s identity, and the related impacts on the emergent access and findings generated.
CHAPTER 2

METHODOLOGY

Introduction

This chapter is an account of the methodology used in this study. This not only describes in detail the mechanics of what happened during the study, but also the social processes that occurred during the interactions in the field, and with the data. As research findings are contingent on many varying social settings, within this study what emerged and how it emerged was closely connected to notions of personal identity (the researcher's and researched). Here this connection or the process of validation according to levels of acceptance and rejection has been called 'cultural validations'.

The methodological stance here takes its momentum from the interaction of roles – biographies, histories, linguistic alliances, as well as differences – and uses these as mechanisms for facilitating insight. In a sense, the frameworks proposed by Stanley and Wise (1993), and critical race theorists such as Ladson-Billings (2003) are a blueprint for interacting, sharing, and co-producing the interaction of an interview.

As the study developed, conceptualisations of research questions became focused and possible contacts in relevant locations grew, so the processes of potential access to both people and their communities grew. Here it is termed potential because only through various processes of ‘screening’ and biographical questioning was there an opportunity to gain access and conduct interviews. A ‘gate keeper’ – a contact connected to a community - was only a first step, and provided an initial entrance (into a cultural and physical world) – either to a person or a community. The remainder of the work would still need to be done in terms of interacting in two languages as and when required, sometimes taking part in helping at events, and at other times revealing elements of my own identity and history. The ‘thread’
mentioned above which is the ‘story’ that weaves through this work is also then present in both the conceptualising and especially the practice of the method. Given that the central thesis of this work seeks to describe and analyse how it is people use active notions of culture and difference in relation to their health, and how this is embedded in everyday life – in contrast to the often passive role created by health and ethnicity discourse, it is analytically useful to observe how this ‘thread’ impacts the entire study.

The first section focuses on the nature of the qualitative methods implemented throughout, as there are areas of research in health which might benefit by taking a more sophisticated view of social action in the relationship between ethnicity and health.

The second part of this chapter focuses on the participants in the study and their ethnic, linguistic and cultural backgrounds. There is also a description and discussion here of the fieldwork sites, the process of gaining informed consent and the general nature of gaining access to groups and people.

The third section describes and discusses how the findings were managed, analysed and interpreted using a grounded theory framework. Here there is detailed discussion about how coding took place at various levels of abstraction, and the intricacies of language involved in doing research across difference and similarity. There is also discussion here regarding theoretical generalisability of the findings, which is then further developed in later in the thesis.

Overall this section constitutes a methodological base on which can be built both the findings and the explanations for them without losing sight of the conceptual threads which run through this work. The methodological base discussed in this section provides an epistemological framework for structuring the theoretical strands of the work, which in this study indicate the socially and culturally embedded experience of diabetes and the active and negotiated order of cultural and ethnic identity.
2.1 QUALITATIVE METHODS

Qualitative methods allowed insights into the cultural and social contexts surrounding the lives of people who had type 2 diabetes and performed the function of being a torch or light to illuminate their experiences. This entering of the ‘cultural domain’ of people (Silverman 1993) is the point of qualitative methods, and depending on the research question, the skills and attitude of the researcher and the particular investigative tool used, an interpretive rendering can be made of people’s social and cultural worlds.

The methodological stance taken here combines the logic of qualitative inquiry (Silverman 1993) which looks to the nature and quality of an experience, with a situated and culturally located acknowledgement of the connection of aspects of identity – both of the researcher and the researched. By problematising the nature of this relationship it is possible to invoke a critical and reflexive sociology of health and ethnicity. This is the practice of the epistemological and ontological underpinning of a study. This study proposes an empirical exploration through the use and development of particular methods, in order to generate a grounded explanation for a phenomena through empirical findings and contribute to the theoretical debate on ethnicity and health.

Qualitative approaches facilitate the elaboration of different dimensions on which the social world operates, by emphasising the “understandings, experiences and imaginings of our research participants...and the significance of the meanings they generate” (Mason 2002: 1). This emphasis on in-depth exploration of the subjects’ lived world is what distinguishes qualitative from quantitative approaches.

There is a long established history in research and practice of qualitative methodology, characterised by Denzin and Lincoln (2005) as moving through various ‘moments’, indicating points at which progress and major shifts in theory and practice might have been identified, and health research is an area where much attention has
been paid with regard to qualitative research (for example Mays and Pope 2000). As Wolcott has argued (1990) there is little need now to constantly defend the qualitative method. Rather there is a need to defend a method, given its ontological and theoretical underpinnings.

Although considerable changes and developments have taken place in the status of interviewing in the social sciences, as early as 1957 some theorists (e.g. Pool 1957, cited in Holstein and Gubrium 1995) were already reformulating the interview setting as constructed and dynamic. Pool disregards the narrow view of the interview as a place where 'truth' can be discovered, but sees it rather as a place where a 'plot' gradually reveals itself throughout the course of the interaction. Proponents of ethnomethodology extend this line of argument by calling it an interpretive accomplishment whereby the process of meaning making is maintained by people constantly calling upon interpretive practices (Holstein and Gubrium 1995). These practices are constituted by those procedures used to represent reality.

2.1.1 Ontological and epistemological considerations

The decision to undertake a qualitative study of the experience of diabetes in a South Asian community reflects the particular ‘world view’ held by myself in relation to sociological research. This study is located theoretically and methodologically in the interpretative paradigm, and is connected through my personal biographical narrative to the subject area of culture and ethnicity. This is really an explication of the theoretical assumptions involved in the research process. As will be discussed later, the process of cultural validations is not simply a methodological toolbox, to be opened and closed when a distinct methodological issue is raised, but rather an explicit statement and analysis of those inter-connective processes that occur between researcher and researched identities throughout the research.

Placing a sociological interest value on type 2 diabetes within the Hindu Gujarati community in England makes a number of assumptions. Firstly it indicates that there
is a health research subject there to be focused on for the purposes of insight into experience, and that having these insights may help in acknowledging the active and dynamic ways in which people use experience and culture to manage their diabetes and health. Secondly, situating the study within an analytical standpoint of symbolic and negotiated markers of difference means that there is a potentially useful way to explore and characterise how ethnicity and culture interact with health status, so that identities can be examined in the context of examining issues of agency and structure. What Mason (2002) calls an ‘intellectual puzzle’ resulted in this study, and is tackled through various theoretical and empirical methods. The selection of the subject matter and the means by which I believed it could be investigated are a reflection of my ontological and epistemological base. Through a combination of my biography and the nature of the research questions, various dimensions of the diabetes experience have been explored in this study. These phenomena I regard as social entities which can be investigated, examined and highlighted through in depth semi-structured interviews and ethnographic work. They also connect my biographical details to the participants through cultural validations. This produces a reflexive sociology which it is hoped not only seeks to understand the experiences of those people who participated, but also examines the role of the researcher and the co-productive nature of the interaction therein.

The current research seeks to investigate the experience of the diabetic patient - in the context of how the illness is perceived and how it affects the everyday lived world; to describe and understand the experience, and the myriad relationships that might exist between the experience of the illness and other possibly crucial and vital elements of respondents’ lives. The main questions addressed in this study are focused to include beliefs about the nature of the illness, possible causes, lay health beliefs, access to health care, migration histories, experience of racism or prejudice, and experience of traditional and herbal medicines. Central to the respondent is also the role the illness plays in their everyday life – and how this might be embedded dynamically within the fabric of their lives. All of these finer points of understanding which aim to be addressed in this qualitative study could not be investigated in the same way using a
quantitative approach. Other, varying and analytically interesting questions might be addressed, but certainly, in terms of depth, understanding and empathic insight, a qualitative methodology was deemed the most appropriate for this study. As Mason emphasises, qualitative approaches allow us to “celebrate richness, depth, nuance, context and multi-dimensionality” of an experience (2002: 1).

2.1.2 Methods used in existing studies

Much of the early research within health and ethnicity was predominantly quantitative, and focused on epidemiological factors (Sashidharan and Francis 1993; Ahmad 1993; Eade 1997). Studies which purported to examine and understand the experience of diabetes in various groups utilised surveys and very little in-depth work had been carried out until relatively recently. Health care access and utilisation has been a prominent feature of these studies (Department of Health 2002, Health Survey of England 1999) but there still exists a dearth of in-depth knowledge regarding the lived experience of South Asian people with diabetes. Where there have been studies which used qualitative methods to understand the experiences of people with diabetes in these communities, these have concentrated on those groups with the highest rates of occurrence – mainly Bangladeshi and Pakistani groups (Greenhalgh 1998). Similarly, Pierce and Armstrong (1996) describe their exploratory study into lay beliefs in an Afro-Caribbean community, but again, very little work in the South Asian community has been carried out. Indeed, Pierce and Armstrong point out that there work has been done specifically on Asian’s beliefs about diabetes quoting Kelleher and Islam (1994). However, this only highlights the need for a more insightful study of health and ethnicity. In the reference above, there is no effort to specify which group of Asians are being referred to, and indeed no effort made to distinguish between groups. As elaborated in earlier sections, there are huge differences in incidence and prevalence rates between the different groups of people termed ‘South Asian’. A statement involving the sole use of the term ‘Asians’ is crude, unsophisticated, and fosters an ethnocentric view of ethnicity and health which contributes very little to our understanding of health and illness beliefs. To date, there
is little or no indication of in-depth qualitative research into the diabetic experience of people in the UK Gujarati community, even though this group constitutes a sizeable portion of the 3.9% of the UK who are of South Asian descent, with diabetes rates in the Indian community at 3-4 times that of non-South Asian counterparts (Health Survey for England 1999). As Hillier and Kelleher spell out, “...emphasis upon the meanings and interpretations through which people make sense of their world” (1996: 4) is how social science research will gain powerful insights into the often-complex relationships between culture, ethnicity and health.

While our understanding of the illness amongst the general White population may be increasing through a variety of qualitative studies, not least through seminal works by Kelleher (1988; 1996), understanding the experiences of minority populations is still somewhat limited. Qualitative studies on South Asian health issues in general - while developing some momentum - are underrepresented in the diabetes literature (exceptions are Greenhalgh et al 1998; Lawton et al 2006). It is increasingly evident such methods are not frequently used to investigate the experience of diabetes in specific South Asian groups, and where they are, there is a distinct lack of theoretical exploration into the dynamic role of culture and ethnicity, with notable exceptions by Kelleher and Islam (1996). There is a gradual increase in the use of qualitative methods in diabetes and ethnicity, for example Lawton et al (2005; 2006), which also make theoretical contributions to the understanding of the health / culture relationship.

Though there will be similarities in experience across the broad grouping ‘South Asian’, there is little to suggest homogeneity. There are myriad differences in how groups conceptualise illnesses, seek help from different sources, practice their beliefs in everyday life, and these peculiarities will be influenced by linguistic, religious, socio-economic and migration-historical factors. As Ramaiya et al (1991) point out in no uncertain terms, that while there may well be a common trend in raised type 2 diabetes prevalence in the South Asian population, there may be significant differences between distinct social and religious groups. Although Ramaiya et al’s study refers to social epidemiological research, the case for attending to subtle
distinctions between groups is made clear. Andrews and Jewson (1993) similarly highlight the need for a more refined group of categories, to avoid ‘empiricising ethnicity’.

Although the current study favours the use of qualitative methods over quantitative (mainly survey) work in the field, it should be noted that survey approaches have made great contributions to elucidating the field of health and ethnicity (Ahmad 1993; Smaje 1995; Mckeigue et al 1988). These contributions have been sophisticated for two major reasons – firstly the use of advanced statistical procedures have allowed theorists to cast a strong shadow of doubt over earlier work which either did not recognise inequalities in health, or did not find it important enough to discuss. Secondly, the variety of ‘culturalist’ approaches utilised in the late 1980’s and early 1990’s were also shown to be flawed, as they ‘pathologised’ (Ahmad 1993) minority health issues and took on a ‘blame the victim’ essence. However, as Ahmad (1993) reminds us, much of this work was also flawed because of the neglect of sociopolitical contexts, and the constant emphasis on culture and biology. Smaje’s (1995) review of literature and studies relating to health and ethnicity also exclusively drew from quantitative and epidemiological studies. Although this is a vital contribution, highlighting lack of both accurate description and explanation of patterns of inequality in the current arena, this work also did not entertain the need for an in-depth examination of minority experiences.

2.1.3 The use of qualitative research in health and ethnicity

There is space and necessity then for a more carefully and culturally rendered picture, but not one which reifies notions of culture and ethnicity; rather the approach required needs to acknowledge that type 2 diabetes is a culturally and socially embedded experience, and that social actors engage actively in using a myriad of cultural resources in their lives to manage their diabetes and manage identities. This more complicated picture has been attempted for the past decade in various guises. As the sociology of health and illness has developed its interest in so-called ‘minority health’
issues, there has been a corresponding increase in the number of studies which examine the experiences of health and illness in minority communities. Complications reside in the actual terms used: ethnicity, race, minority, lifestyle, culture; all of these are definitional contingencies, which are often picked to explain a particular occurrence. As Smaje (2000) highlights, race and ethnicity are to be seen as categories which are constructed as part of a socio-historical process, and which undoubtedly become implicated in the behaviours and life chances of people. Sociological investigation necessarily needs to provide what Smaje terms "a critique of ideology"—and in relation to health, illness and ethnicity, this means locating the concepts of race and ethnicity in a wider socio-historical context, thereby rendering them as "ideological categories...and not analytical concepts" (2000: 114). Part of this project of re-examining these concepts is to look to qualitative research in health and ethnicity, which articulates peoples’ experiences in terms of their own voices, not the formulations imposed by ideologically imposed frameworks. While Smaje turns to structural forces in knowledge production which influence the research agenda, this study looks to local and individual forces and the way in which they mesh with other social phenomena to form the sociological context of diabetes experience.

This deficiency in research forms part of the rationale to employ qualitative methods in this study. It seeks to understand the experience, and those aspects of the experience which may or may not have commonalities with other groups; identify those aspects of the experience which may be different to those illuminated in previous studies; and to examine the possibility of a range of factors in the diabetic experience which are contributing to the overall burden of illness. However because studies have not been conducted in this community, these are not yet revealed and therefore not understood. Qualitative, interpretive and situated methods for generating data were deemed most appropriate in eliciting data which most clearly resemble the structures and meanings used by respondents (Fielding & Fielding 1986).
2.1.4 Difference, ethnicity and the interview

The growth of literature focusing on the politics and ethics of research has grown considerably over the last twenty years. Much of this research has highlighted the need to sensitize researchers to the everyday realities of research when crossing boundaries of class, race and gender. While feminist critiques of traditional and 'masculine' modes of operation in research have forged a distinct direction within the politics of research (Oakley 1981; Finch 1984), this movement has also led to invaluable intellectual by-products. The feminist directed 'unpacking' of masculine notions of 'objectivity' in knowledge claims served to unleash a deserved attack on non-egalitarian forms of research, leading to research relationships of a different nature (Stanley and Wise 1993). This lobby for a change also connects to the growing arena of the role of ethnicity in research. There has been criticism of research carried out by white researchers into 'black' experiences for misrepresentation, or the non-applicability of the 'white researcher – black respondent' coupling. Developments in this area have led to insights regarding potential problems in understanding, interpretation, and power. The binary nature of the coupling 'black/white' as reflected in research settings has been questioned for neglecting the complexity and diversity of experiences in the process of the research, and for resulting in a theoretical sophistication, but paucity in actual practice (Song and Parker 1995). This has a direct relevance to this study of Gujarati type 2 diabetics – since my own ethnic, national and linguistic identity reflects and interweaves with that of the participants. The production of the interview situation is shaped by cultural identities and this is often neglected in research.

The rationale for investigating the potentials and possibilities – theoretical and practical – of the interaction between identity and research was the linking at different levels of the identities of participants and myself. It was because we shared fragments of identity at linguistic, religious, national, class and ethnic levels that a partial examination needs to take place of this phenomenon.
Gunaratnam (2003) highlighted the problems of interviewing across difference by posing the question of how white researchers can somehow bridge the gap between themselves and the minorities they want to study, by running the risk of what Anderson (1993) called distorting sociological accounts in terms of race, gender and class. It would be overly simplistic and a huge error to regard this study as unproblematic in this aspect, simply because the interviewer shares certain dimensions of his identity with the study group. There are issues here related to constructions of ‘authenticity’ and their impact on the research. Since no two research interviews will be identical there are bound to be many issues at play while the production of the interview is underway. These are important considerations, and as Smaje (1995) has warned against ‘ideological categories’, so Gunaratnam (2003) warns against ‘categorical thinking’. I aim to avoid the tendency to simplify and reduce experiences on the basis of differences and commonalities. Rather than emulating some model of natural science by attempting to control variables which in a socially constructed reality are beyond control, this study hopes to actively engage in the dynamic processes involved in the ways in which two identities come together, sometimes connecting and at other times clashing. It is perhaps in the process of negotiating the interaction of differences and similarities that the lived experience of a person with diabetes can be understood. As Song and Parker state, the “unfolding of the researcher’s and interviewee’s cultural identities is central to the ways in which the researcher and researched position themselves in relation to the ‘other’” (1995: 243).

Choosing an appropriate research design for this study was a decision which involved looking deeper into the ontological and epistemological grounding of both my own philosophies of research, and the kind of research outcome that was intended. As Mason (2002) argues, it involves an accurate reflection which clearly demonstrates the researchers position on their concept of social reality – i.e. What types of social reality exist? And how can this be investigated, measured, analysed and reported?
2.1.5 The research interview

“Interviewing is rather like marriage: everybody knows what it is, an awful lot of people do it, and yet behind each closed front door there is a world of secrets.” (Oakley 1981: 243)

Given that interviewing has many forms and disciplinary locations in social science research, it is perhaps no wonder that there are many ways of conceptualising, conducting, generating and analysing interview data. The interview has been regarded as the *sine qua non* in the social science methodology tool kit (Lawton 2003), representing what seems to be the ideal form of eliciting information through respondent accounts. However, it is not the only way to generate rich qualitative data, as Rier (2000) examined through necessity an alternative method for account production (narrating experiences himself by writing during his own illness) and Lawton has called on medical sociologists to be more imaginative in the quest for qualitative data.

Extending the arguments above apropos the (over)use of interviews to generate data, Silverman (1993) uses the term the ‘interview society’ – to describe the ubiquity of interview data generation from mass media to research studies. As a way of generating data in and about the social world, it is as yet unrivalled. While the generic term can apply to an enormous array of differing ways of interviewing – from quantitatively based highly structured interviews to unstructured, free flowing “guided conversations” (Lofland 1995), each rooted in its own epistemological grounding, they are all examples of interactional forms. It is through this interactional base that this study forms its interview practice, taking the interview as an ‘*in situ*’ (Silverman 1993) product with its emphasis on the nature of collaborative meaning production. The study also situates the interview very much within discussions of symbolic markers of similarity and difference which have an impact on the outcome.
This manner of according an ‘active’, alive and co-productive status to the interview situation is based on the interpretive, ethnomethodological and constructionist arguments. These traditions lend themselves neatly to the epistemological foundations of this study – that by entering each others’ cultural and social domains the people involved in the interview are both creating and generating the interview data.

It is to this methodological thread that an ontological grounding can be added. As Fielding & Fielding (1986) succinctly point out, methods are always rooted in theory. If they are rooted in theory, then there has to be a world view on which both the method and theory stand. This requirement to base the methodological decision in some form of robust epistemological and ontological thinking is emphasised in Mason’s warning against empty theorising (2002). The active interview then, as opposed to the traditional positivistic transmittal of information interview, provides an opportunity to regard the interaction differently. In the process of the interview, the respondent will not only answer questions, but also will modify, shape, add to and take away from the talk they are presenting and offering. The responses then are constantly being assembled and modified (Silverman 1993) in the course of the interview – so the sole search for an all-encompassing objective truth is rendered futile. In relation to the interactions within this study then, it was the process as an interactional encounter – with both sides of the interaction generating the result – which made the interviews active, but also made the interactions active. While participants’ talk in the interviews can be regarded as accounts (Radley and Billig 1996) they can also be regarded as interactional sequences between myself and the participants, involving my experience and identity accounts. While interviews come in many shapes and forms, the type used in this research are semi-structured interviews, aided by a topic guide to assist in the questioning, which in accordance to a grounded theory framework is modified and developed in relation to emerging categories within the data (Strauss and Corbin 1990).
2.2 THE PARTICIPANTS AND THE RESEARCH PROCESS

The participants were twenty Hindu Gujarati type 2 diabetics, in four locations in England (Birmingham, Leicester, Crawley and Preston). The majority of the participants were located in two of these cities (Birmingham and Leicester) which have high concentrations of South Asian populations in general, and Hindu Gujaratis specifically. This study used theoretical / purposive (Strauss and Corbin 1990) and snowball sampling (Hughes et al 1995) to recruit participants and generate data. There was an even gender spread of participants recruited through these methods. Nineteen type 2 diabetics and one type 1 diabetic Hindu Gujaratis were interviewed, with ages ranging from 40 to 88 (8 women and 12 men). I gained access to community leaders and other ‘gatekeepers’ who facilitated my presence at a number of gatherings in local temples and community centres. Contact details were collected from potential participants, who were then telephoned to discuss the possibility of an interview.

Before the fieldwork began, ethical approval was gained from a University Ethics Committee (appendix a). Informed consent forms (appendix c) which I explained in Gujarati and English were presented and signed before the interview started. A topic guide (appendix d) was used to guide the process of questioning and interacting with the participant, and focused on the experience and management of diabetes within the context of migration histories, and the use of different medical and healing systems. The interviews lasted between forty and one hundred minutes. They were audio taped, translated and transcribed. The data were generated and analysed using a grounded theory framework so that the process of theory building was rooted in the data (Glaser and Strauss 1967). In practice the process was more akin to Blaikie’s abductive strategy (2000) – leading to a constant to and fro movement from data generation, analysis and emergent ‘theory’ testing. In accordance with the generally accepted mode of theoretical sampling in qualitative research (Mason 2002) the recruitment of participants and search for data ended when the emergence of new codes and categories began to lessen.
Most of the twenty interviews took place in private homes and more often than not, there was a third person present, usually an immediate relative. In many cases the interview situation was characterised by this ‘triad’ dynamic. Contrary to Boeije’s (2004) suggestion that this ‘third’ person decreases validity, here it was seen as a resource for the study, which could be utilised for a rich account of the socially and culturally embedded diabetes experience. This seemed an appropriate strategy since the management of type 2 diabetes was rarely a lone biographical project, but rather a personal and social activity carried out in the context of relationships (Peyrot et al 1987). People were aided by significant others in complex webs of knowledge, belief and products, so it seemed appropriate that a qualitative and situated sociology could engage in these relations rather than negate or ignore their value.

The rationale for these criteria was both analytical and logistic. My research interests have centred on the experiences of South Asians in the UK in general, with a special focus on health and illness. These interests also extend to the role of traditional and lay beliefs, and the ways in which migration experiences, and the general cultural experience, or expressions of ‘cultural navigation’ (Ballard 1994) manifest themselves in everyday life. For this reason, individuals describing themselves as belonging within a particular faith group — Hindus — were chosen. There was also a practical reason for this — I have some experience and knowledge about the faith so relating to the experiences, and being able to connect and share within these frameworks were seen as elements that might have made accessing the cultural domain easier. The age criteria were chosen for two reasons. It has been well established and documented that there are generational differences in experiences between migrants of different age groups, with a variety of factors playing roles in how individuals traverse the varying cultural universes, employing linguistic, cultural, religious and social techniques to accomplish this (Bhachu 1986). Because of this distinction, I focused on the experiences of first generation migrants from South Asia, in order not to homogenise groups which have distinct characteristic experiences. The second reason for choosing this age group is linked to the nature of type 2 diabetes. As it is also known as ‘mature’ or ‘later onset’ diabetes, the age at which diagnosis takes place is usually
around 40 years of age, although data now indicates it is appearing in people much younger than this (Ehtisham et al 2000).

As already shown by numerous authors (Visram 2002; Ballard 1994; Hill 1969; Hiro 1992) there is a long history of migration from South Asian countries to the UK. In order to explain precisely who constitutes the Gujarati community in Britain, it is important to accord some notion of historical sequence to the development of this diaspora. To echo Garland’s (2001) arguments apropos a “history of the present”, it is vital that we illuminate the past, through its relationship to the present. The emphasis here is on history informing our analyses, rather than delving into an archival model of descriptive science. Many of the informants in the interviews talked to me about their lives here in this country and the vicissitudes of life in a new land, where hostility and aggression were often the norm. However they also talked about some aspects of their lives both in India and Africa, including the process of settling in the UK. These experiences are inextricably connected to the overall experience the study is investigating – diabetes being one aspect of this range.

2.2.1 Gujarat

Gujarat, a state in India lies north of Mumbai on its West coast. Its location on the coast made it an ideal place for trade routes to a variety of locations to be set up, including Africa and the Middle East. Internal trading routes also benefited from Gujarat, as archaeological evidence demonstrates evidence of trading with Mesopotamia in the 2\textsuperscript{nd} millennia BCE, and many later references during Buddhist, Muslim and Hindu presences to the thriving culture of trade, commerce, hard work, frugal living and entrepreneurial entities (Dwyer 1994). These traditions continued as the 19\textsuperscript{th} century progressed, with Gujarati migration being reinforced firstly by sheer historical force – four hundred years of overseas trade - and secondly the British colonial expansion into East Africa, bringing with it many socio-economic and political as well as cultural changes (Warrier 1994).
Many of the informants in the interviews locate their experiences within this historically and identity centred landscape – a concept Ballard (1994) discusses in detail – the “desh pardesh” phenomenon (literally – “home from home”, or “at home abroad”) and will be discussed in more detail later.

2.2.2 Caste considerations

Additional and important information about these informants is their caste. This is an important dimension to include here, as it helps to describe a vital organising feature of the community – many of the Hindu Gujarati communities both in India and the diaspora are organised around the caste system. Here I refer to the term as one based in Hindu history, mythology and cosmology, but also in the modern conceptualisation of a logistic, community, and organising principle. There are detailed accounts elsewhere discussing the logic and nature of the caste system as it operates in both India and the diaspora (Ballard 1994; Quigley 1991; Smaje 2000), here I am highlighting some of the more immediately pertinent features.

Caste, or jati, is still very probably a source of Western indignation and repulsion. The thought of millions of people being subjugated and discriminated against because of a divinely and birth ordained place in the societal and economic hierarchy is – anecdotally at least – the impetus for many stereotypes and misconceptions about the people of the Indian subcontinent and the diasporic populations. Of course when one equates the very basis of the Hindu caste system – hierarchical structure – with poverty, repression and exploitation, it quickly becomes clear that every society has and still has some sort of caste system in operation. Within a more socio-historically located discourse, the jati no longer appears as a crude and cruel subjugating practice, but rather a universal practice of categorisation according to a variety of factors – economic, religious, linguistic, labour divisive and ideological. The ideological foundations of caste are crucial in appreciating the importance of this category of difference within this study. This is by no means negating the ideological and material
basis of repressive impacts on people's lives and societal structure, but rather a rendering of the concept in a more critical, lived and culturally complex light.

In Hindu cosmology where the local concept of caste is sourced, the cosmic order is maintained by differentiation and interdependence of parts. The social order is seen as constituted by an interrelated system of parts cooperating to contribute to the whole. Hindu society is a society of people carrying out functions and playing certain roles ascribed to them by birth – priests "perform rituals to please the gods, kings rule, merchants trade, farmers cultivate their land" (Ballard 1994: 25). In principle there is little or no movement allowed either up or down the hierarchy, and perhaps this narrow conception is what ethnocentric thinking relies on to objectify and distance the idea of caste from its own supposed utopian and meritocratic ideals. Throughout the subcontinent, the population is divided into jatis. As Ballard (1994) has shown these fixed positions can be misleading in how groups of people are represented. The unity and solidarity within the caste is held together by common interests, entering into effective collective bargaining, reinforced by religion and culture. Although this is an oversimplification it makes the case that caste is not an idea that remote from western ideas of class. As Dwyer (1994) has shown, the flexibility within a caste to exploit opportunities which might result in an upward mobility have been demonstrated before, for example by the Gujarat merchant castes pursuing a trade vacuum before the British arrived in India.

All the participants in this study belong to or at least categorised themselves as belonging to a caste – or jati. Some of them have a common link in that they attended the regular community event at their local Hindu temple / community centre. Of the two main 'permanent sites' (collective gatherings which had a building allocated to them) that I visited, one was a group organised by and run for members of a caste. In the other there was no caste organising principle and the people who attended there were of many different castes. One of the participants of this study held a prominent position on the national board of representatives for their cultural society, highlighting the issue that far from a fixed a stereotypical idea, here caste is an organising
principle, utilised to mobilise resources, both financial and non-financial. Other participants were members of different castes, and attended local elder’s community events in temples where there was no caste specified, and inclusion of all religions and ethnicities was encouraged.

2.2.3 The fieldwork ‘sites’

The ‘sites’ of research within this study have varied according to the needs of the research and invariably the practical and logistic confines that are part of the process. Most of the interviews took place in people’s homes, and therefore the idea of ‘site’ is a contrivance, since it encourages the construction of a separate entity where ‘diabetes’ takes place. Rather, the sites in this study were wherever the participants chose to be when they were talking to me, and wherever I chose to be in any preliminary ethnographic observations I made. This made sense given people did not exist in binary categories of diabetes / non-diabetes, or temple / not at temple; rather there was inextricable weaving of many threads to their social and cultural lives.

There were two main locations where much of the sampling took place, and one additional organised event where I was able to approach and talk to people, make appointments, gather information, and generally observe, make notes and engage. Two sites of the study were located at Hindu temples which also served as local community centres. Within these sites I was able to approach ‘gate keepers’ whom I had telephoned and / or met earlier. From this introduction I was able to talk to people, engage with them and ask questions – in some cases I was questioned immediately about diabetes and its medical features – the assumption that I was a medical expert of some sort was at times challenging. In many other cases I would attempt to note down details and make future appointments to see people – but this was often difficult. Although the term ‘research’ was familiar to people, it was almost always in relation to medical research and not social research, this however became easier with time and familiarity.
The two community centres which were visited acted as sample generators and introductory access points to the potential research participants. One was located in a community centre in Leicester, an East Midlands city, where surrounding areas held a large concentration of Hindu Gujarati people. The other location was in the same city, at a Hindu temple which also served as a community centre. Each held regular, weekly events for the elderly population, inviting health visitors and various charity organisations which may have been involved in collaborative work with them. The main established difference between the two sites was that the former was organised around the notional idea of caste, or jati. Both of these organisations were run by fully functional and officially recognised cultural committees, acquiring funding and support from both donations and various government and charity sources. The organisation of each one of these sites is an interesting route for future potential studies, as there are many sociological and anthropological themes which can be pursued in this area. This however is not the thrust of the current study. It may be sufficient to state that each one of these sites was a focal point for men and women in respective communities to come together, share stories, socialise, have lunch together, and with regular health related visits from external agencies, engage in these aspects of social and cultural life. The third site was a religious and spiritual event organised to host a visit from a speaker from India. This has been a regular event and the speaker, a man feted in modern Hindu spiritual discourse regularly visits various locations around the globe, in what are very large, mass populated events. One of my contacts within the community was able to connect me with a member of the helping staff there, from which point I was able to identify, talk with and interview a number of participants.

These locations were one part of the research process, and in many cases ‘set up’ the possibility of many of the interviews in people’s homes so should be regarded as such, rather than stand alone sites of ethnographic observation. The term ‘sites’ then is a flexible one as research within the boundaries of a public ‘site’ often led to interview possibilities outside of this boundary in peoples private arenas.
2.2.4 Ethical issues in practice

There is of course a strong requirement for this study to operate within the parameters and guidelines of ethical research practice. Ethical consent was applied for and granted from the University of Surrey Research Ethics Committee in February 2005 (appendix a). The formal procedure of applying for and gaining ethical clearance is clearly an important and required aspect of conducting this type of research, but does not form the only important ethical feature of the research. The formal requirements ensure that the safety of participants and researcher is of utmost importance, and critical issues such as risk to both parties are engaged with and dealt with. These procedures also require the researcher to make explicit the data protection laws in place and the guarantee of anonymity for participants. The informed consent form (discussed in more detail below) also provides the participant with the possibility of withdrawal from the study at any time. These formal ethical procedures constitute the groundwork for research, but also require input from the everyday practices of ethics in research. This concerns the wider implications of the research on an ethical level. Here I draw on the issues which often arose as the work was in process. As Mason (1996) argues, the often intimate nature of qualitative work means engagement in both the public and private lives of people. In addition the emergent and dynamic nature of the research often results in unexpected changes within the research arena one is in. While the overall structure of the formal procedure remains, often field work and interactions therein can throw up situations which require a dynamic and situated approach. The safety and welfare of participants is still intact, but the cultural, social and personal domains one has entered then require an additional informed practical field ethic.

One example from the field work helps to illustrate this situation. During a visit to a community centre / temple in Birmingham I approached people to ask them if they were interested in talking to me about their diabetes (having gained clearance from the gatekeeper and organisation head first). As I approached, having explained who I was and what I was doing there, a woman alerted me to the fact that she did not have a
bath seat installed in her bathroom, that she had been waiting a long time, and asked if I could help her. I was at first unsure of what to do, but informed her that I was doing research into diabetes experiences in the community. Undeterred she asked again, and perceiving that this was a serious matter for this woman, I told her I was sure it would be dealt with as soon as the local authorities could deal with it, and that these things often take time. This appeared to be a sufficient response as she did not ask again. The next day I returned and on seeing me the same woman approached me again – this time thanking me. Apparently the local authorities had visited in between my visits and had installed a bath seat to her full satisfaction. She was extremely grateful and expressed her thanks at such speedy service, which she apparently attributed to my intervention. I responded by saying how glad I was that her problem was solved and that she was happy with the outcome. My response here could have been to strictly adhere to formal ethical guidelines, in which case I would have insisted in the first meeting that I could not help her at all, and in the second meeting that the resolution had absolutely nothing to do with me. These however seemed far from facilitative to field relations, and given that she was not being interviewed and there seemed to be little apparent negative impact on her within this interaction, it certainly seemed socially and culturally reasonable to adopt this course of action. I was confident that the study retained its ethical grounding and used this experience to inform the methodological and analytical issues in the study.

Essentially my identity as strictly a researcher was changed the moment I stepped into the lived, social and cultural domain I was interested in. Within this I was mistaken for someone who carried some form of power or influence to change certain aspects of people’s lives. Herein lies the ethical crux – that there are issues of power and control which without reflexivity and intra / interpersonal negotiation, can have negative impacts on people involved in the study. This suggests that while formal, professional and discipline specific ethical guidelines are essential to research, there is also a need for a working-practice, reflexive ethical scrutiny, which takes into account the various and negotiated roles of researcher and researched identities.
2.2.5 Informed Consent

Each participant was given an informed consent form to read and sign. Anyone who was not able to read the form in English was given the opportunity to keep the form, and have it read and translated for them by someone they knew. I also read out the form to them, translating where necessary. This would give them a chance to discuss the consent form with someone whom they trusted and felt able to share their thoughts with. Those participants whom I felt were not entirely sure about signing the form were reassured that they could speak to someone in their family or social circle before they signed the form.

While the study fully conformed to the ethical guidelines set out by the University of Surrey and the British Sociological Association’s ethical framework for research in relation to Informed Consent, this raises an interesting set of issues. The subject or concept of informed consent is not something most of the participants were aware of, familiar with or interested in. On the whole when informed about the forms, they told me that they would sign anything they needed to, as long as it was helpful to me. In many cases they would also question my asking their permission, stating that there was no need to ask, as there was an inherent trust by virtue of my presence in their house, and them talking to me about this important health subject. This raised issues of both conceptual conflict between what I term here the ‘cultural versus professional’ validations conundrum, and issues of vulnerability and the inherent trust that is built up in this type of research, which can be a problem if personal ethical principles are not rigorous enough. By this I question what can in some cases be taken as ‘insider’ knowledge of a cultural grouping, to the extent that informed consent is taken for granted. I was very aware that by assuming the role of a trustee, it was possible to forgo the ‘paper work’ involved and get straight to the interview or talking. The Informed Consent guidelines were adhered to nevertheless, and the ‘professional’ or ‘expert’ system of ethical guidelines was supplemented by the emergent system of ‘cultural validations’.
2.2.6 Gaining access

The process of getting access was always going to involve a gate keeping process – whereby someone whom I knew to have study relevant contacts would be able to point me in the direction of potential informants. This happened on several occasions in different ways, and was driven by varying factors. My primary contact was a researcher whom I knew professionally and socially to be working in the field of social and health sciences, within Birmingham. Once I had explained my study needs, I was given the contact number of a potential participant, who had already been briefed by my contact about the study, provided them with my details, as well as details of the study. He was also given my contact details so that he could initiate contact if he preferred. I then telephoned the participant once I learnt that this was a suitable step to take, to arrange the interview and provide more information about the study. I was also provided with a link to various gatekeepers – a person who played a role in the community centres / temples in Birmingham and Leicester – and through them was able to negotiate and arrange visits to these places. The visits allowed me to sometimes conduct interviews ‘on site’, and at other times invite people to have an interview with me in their homes, depending on where they preferred. Having a ‘gatekeeper’ of course is not without its issues - the ‘key informant’ will hold a particular position within this arena, and will therefore be part of those power relations – experiences and relations perhaps different to the participants to be interviewed. This polarity between insider and outsider status has been critiqued, because as Merton (1972) argued, people do not simply have one organising status, but complex and interrelated sets. Therefore within this work the gatekeepers’ role in facilitating access is viewed as proccessual, dynamic and part of the overall accessing of various cultural domains. It is also deemed essential as part of the process of cultural validations, since acceptance and rejection do not take place in isolation, but often with reference to other social actors.
2.3 THE DATA MANAGEMENT AND ANALYSIS

As with most qualitative data there is an issue of managing the sheer bulk of the data. In this study the data was in the form of interviews, which were conducted in English and/or Gujarati. These were tape recorded and then transcribed (and translated, discussed below) using a transcribing machine which facilitated a speedier process. Once the data were in a textual form, they were imported into qualitative analysis software (Atlas.ti® V5.0) which greatly enhanced the management, retrieval and analysis process. The open coding took place both on hard copies of the transcripts and ‘on screen’ using the software. Where the coding took the former, the exact process was repeated on screen so that there was a standard and systematic procedure for all interviews. Focused coding was usually carried out using software, due to the speed with which it was possible to access information, notes and memos. The other functions used in Atlas were the Family function and Networking function – these will be spelled out in more detail later in this section. The analysis in general began as soon as the interview was completed, or as soon as possible afterwards in various circumstances. This took the form of impressions, notes, ‘memos’ and entries into a journal (maintained throughout the process). While these have not been presented in this study, they performed a valuable function by connecting cognitive processes to concrete occurrences, and aided the overall theoretical schema building. These accumulative processes resulted in an account of people’s stories of diabetes and the social and culturally embedded nature of health and illness experience. The resulting explanations are linked directly to people’s voices, conforming to the core precepts of grounded theory frameworks.

2.3.1 Transcription and translation

The decision to conduct the study in both Gujarati and English was based on entering the ‘cultural domain’ (Silverman 1993) of the people who were willingly opening their homes and lives to me. This ‘life world’ (Schutz 1966) was constituted in part by
the language that was spoken and was crucial to understanding and answering the research questions.

The research questions within this study focus on the experiences of type 2 diabetes in the lives of Gujarati Hindus in several locations in the UK. This involves equal competences in being able to speak Gujarati and English. Since my own mother tongue is Gujarati, communication, translation and transcription would be less of a problem than if I had no proficiency in Gujarati. The process of social action requires language to facilitate it, and accepting the role of language as a system of symbols and gestures to communicate universes of meaning, requires acceptance of its crucial and central role. Hence the importance given to the process of cultural validation, for it is mainly though not entirely through linguistic connection that this process of screening, acceptance or rejection takes place. During the fieldwork, were I not able to speak the language as well as converse about commonalities in histories, then access may not have been gained so easily; the kinds of topics discussed may have been different; the level of disclosure may have varied and the vital social connection which is such a powerful theme here may have been lost.

This of course does not necessarily mean that similar research by someone else who speaks only English would produce fewer insights; simply that the research outcome would be different, as would the relationship between researcher and researched. The importance of language of course has been long established by anthropologists, but sociologists undertaking this kind of work have also relied on having the linguistic connection (e.g. Kelleher and Islam 1996; Reed 2003; Bradby 2002).

In many ways, being able to conduct the interviews in one language most familiar to the informant, but having the option to also conduct them in English performed a useful conceptual function. On a practical and methodological level it made the informant more comfortable; but on another level, it symbolised the relationship which first generation migrants have with a 'host' country. Being a part of the interview interaction where I was able to enter a cultural world and linguistic world,
represented to some extent *modernity* through the generation of intellectual knowledge, and *tradition* through a language which was a part of the respondent's history, echoing Giddens’s dialectic of the local and global (1991:22).

The audio tapes were transcribed and translated simultaneously, in order that an interview transcript (and therefore a readable text file) could be created, ready for coding and retrieval via computer software. The mechanical process of translating for this study was of course labour intensive, and sometimes required listening to the same audio tape or section of audio tape many times over. As expected however with qualitative analysis, most of the time this resulted in familiarity and closeness to the data, although sometimes resulted in frustration and over-work. While no translation service was used for the study, I assessed myself to be competent in the language by my own standards of evaluation (Gujarati being my mother tongue and a language I speak everyday), and by others. This was not a separate ‘evaluation’ process, but rather an ad-hoc checking process. I visited people in other communities, engaged in social events, and in the process of socialising normally, engaged in lengthy and detailed conversations. The result was that smooth and substantial interactions occurred, and there were no misunderstandings, misconceptions, silences or stumbling due to lack of vocabulary. This was a form of validation which provided some reassurance for the study. An additional consideration is that of consistency; because a translator was not used in the fieldwork or interviews, there was no logic to using one for the transcription process.

As with all translation procedures there is the added obstacle of non-literal interpretation. Where possible the interviews have been transcribed verbatim and literally, but in some places the literal translation would have rendered the data meaningless, therefore appropriate interpretations have been made. An additional consideration is that of researching in multiple languages. Regarding interviewing, there is a complex interaction of cultural ‘domains’, in that while attending to the social interactional nature of the interview, there is also a need to observe the topic guide (written in English), ask questions or raise issues (involving reading the topic
guide, translating into Gujarati, and asking the question in a form which simultaneously maintains the essence of the research questions, but is accessible for the respondent), taking notes (in English), and responding (in Gujarati). Needless to say this is a complex and involved procedure, which most of the time, is part of the normal social routine, but unconsciously requires many different tasks to be coordinated.

The process of translation has been described in some detail by specialists elsewhere (Birbili 2000), and in many ways is peripheral to this study, because the translation is not simply of words and how they constitute language, but rather on how these words constitute social action. Bradby (2002) has succinctly emphasised the importance of language and linguistic competencies, or at least the cooperation with linguistic expertise when working in the arena of ethnicity and health. I would extend this argument further, and argue that not only is this competency required, but a critical appraisal of identities is required for the research to be able to translate meanings – as created and sustained by participants. This means that not only might language be important but the cultural and social complexities of context need to be understood, in ways which will allow a connection to participants to be set up and maintained. In this study I call this dynamic process 'cultural validations'.

While within this study the argument stops short of the traditional and now somewhat outdated ideas of 'matching' with reference to 'ethnicity', I do argue that 'competency' is rather more than speaking the language. This was evident throughout the process of carrying out research in this study. From initial phone calls to both primary contacts, gatekeepers and participants, to attending community centre events, through to the interviews, it was clear that there was much more to this process than simply 'knowing' a language; it was knowing the cultural, religious, linguistic, caste, biographical and historical context which provided the framework. Cultural idioms, sayings, proverbs, and references to villages and names in Gujarat were part of the process of 'cultural validation'. For example when a participant asked which village my parents were from, it was imperative that I knew this in detail. The 'added bonus'
of this would be a commonality and connection with the participant, a sharing of cultural and ethnic details which did not run the risk of compromising the study, allowed a rapport to develop, and demonstrated my suitability for conversation.

As Bradby (2002) elucidates, anthropology has long taken language expertise to be the cornerstone of its work, and without this, understanding how a societal framework works would not be possible. Sociology then, as Bradby explains has not traditionally had this concern, for a variety of reasons – some related to the development of sub-fields such as socio-linguistics, while others may be more related to Britain’s’ colonial past and assimilation models of thought. As the profession develops and the themes of its research portfolio change, so does the makeup of the membership of the profession, leading to new forms of hybridity in identity in research.

2.3.2 Initial phases in analyses – bridge building

While the process of analysis starts long before any formal procedure is commenced the translation of the data presented new and added challenges for me. The analytical process was more than extracting participants’ meanings from the talk interaction; it was moving from one language to another, and then establishing meaning. While this was certainly challenging, it was not as problematic as initially predicted. The financial and time restraints on the study meant that acquiring the services of professional translation service - though considered - was not feasible. However within this study, it is precisely this requirement to be intimate with the data which allowed an in-depth focus on the data. The process of analysing qualitative data generally involves ‘immersion’, and a relationship with the generation of data. In this study there was an opportunity to be further immersed in the data at both a cultural and linguistic level. One might argue that all data requires these two levels of immersion, but it could equally be argued that in the context of the personal biographies and cultural validations required for this research to take place, this took on new and added dimensions for the analysis. For example, when a participant talked about migrating from Africa to the UK and their experiences of hostility and difficulty
it was inevitable that this would strike a powerful and resonant chord with my own experiences, but rather than cloud any issues it allowed me to pursue the issue further, and in more detail.

Typically after the interview I would dictate a summary of the interaction, highlighting any special circumstances, issues or problems that might have come up in the interview, negative or positive. I would also establish a first impression of the main types of descriptive category that were emerging from the interview — though this was a selective process as it was done from memory. Used alone as the sole method of coding and analysis, this would not allow robust conclusions to be drawn, and suffer charges of anecdotalism and invalidity. However used as a complement to the process, this was a useful tool. In a sense, this concretising of first impressions, though coloured by what would be recent and immediate memory of the interaction was also a good way to establish intuitively my ideas of major themes. It would also serve as a useful record of events because of the factual data recorded (either by audio tape or by written record).

Secondly, having gained some distance from the interview, I would listen to the entire interaction on audio tape, making notes of descriptive categories, superficial elements, (but not restricted to these), and ideas that would be useful later in the study. Having done this, the next step taken was the creating of a ‘mind-map’ of themes, which essentially was a pictorial representation of a summary of the themes that were emerging immediately. Though concentrating on the ‘lower level’ (descriptive) categories, other more abstract and analytical categories were also noted, and kept aside for later and complementary use. The third step in the process was making a list of the major categories that had occurred thus far in the data on an index card system. These preceding three steps allowed a conceptual bridge to be created between the interview situation, and the computer software that would inevitably allow a more efficient and speedy management and text retrieval process.
As mentioned earlier, the qualitative software package Atlas.ti® V5.0 was used for the management and analysis of the findings. There is room in qualitative analysis to accommodate both ‘pen-and-paper’ and computer protocols for carrying out the analysis. The manual method was often conducted in situations where either it was not practical to use the computer, or it was simply not preferred – sometimes it is the tactile nature of drawing lines and diagrams that facilitates the creative process in making conceptual connections. At other times and certainly in the later and advanced stages of the study the computer was used most of the time. It should also be noted that any information created manually was also then placed within the project on computer, to avoid important omissions.

2.3.3 Data Management and Coding

Coding – the process of establishing what the data consist of and the kinds of things people in the study talked about took place in a formal sense when transcripts were available, so that it was possible either manually (meaning pen and paper protocol) or using computer software to carry out open coding. As Charmaz (2006) argues, this initial open coding assisted the transition from raw data to analytical theory. It should be noted however that many of the initial codes were also ones which were created in memos, in fieldwork notes books, and on pieces of paper which were inserted into study documents either during fieldwork or at some point afterwards, thus reflecting the somewhat personal and situated nature of analysis. These open codes formed the basis of later coding work and did not interfere with the process of working out how to characterise the actions in the text of the interview, but instead often worked as anchors which connected the transcript to the lived experience of the interview, evoking memories of the interaction. This was particularly useful for regaining a sense of the socially and culturally embedded nature of the interview.

Some of the initial codes that were generated during the process of open initial coding were ‘in vivo’, so that they are named exactly as they appear in the text of the participant. This was useful in a number of ways; it allowed for the capture of an idea
or notion which was completely and most appropriately expressed by the participant, and re-naming it would have been analytically pointless; maintaining in vivo codes helped to ground the theoretical progress – it provided a link between abstracting and the actual words spoken by the participants, so giving the code much more significance. This ‘in vivo’ coding was done selectively, was not widespread and restricted to occurrences of words or phrases which captured a symbolic or significant notion or idea, such as ‘becoming multi’ or ‘my background’.

These codes were then examined in terms of the kind of content they contained – key questions asked of the codes were: How did they differ? How were they the same and what connections existed between them? By asking these key questions it was possible to move to the next phase of analysis which was focused coding. By this time the analytical process was being vastly aided by the efficiency and speed of Atlas, so that functions such as string searches, as well as more focused functions such as examining all the text connected to a code were useful. By progressing in this fashion, the initial codes were transformed into code families, which were given category names. Categorising – developing analytical concepts which can house common themes and patterns was then explored through the ‘network view’ function. This function allows the viewing of a code family – categories – through diagrammatic form, and when each code within the family is clicked upon, it is possible to view all the data which has been coded there. This facilitated exploring connections between codes and categories, but also between families themselves, as there were overlaps.

Being able to attend to the unitary and connected nature of the data also allowed for a theoretical thread to develop. The initial codes already provided a glimpse of the findings – albeit in un-abstracted terms. Codes such as “you have to be your own doctor”, “total control”, “becoming multi”, “mixing with many people”, “balancing your books” and “herbal remedies”, to name but a few provided an idea that there was a sense of active social and cultural meaning making happening, and that within the interviews there was probably more which could be examined to establish what this meaning referred to. Given that I had identified a symbolic interactionist informed
approach as one which might be useful for the study of a negotiated order of identity in the context of a chronic condition such as type 2 diabetes, it was clear that the beginnings of theoretical formulation were appearing. The exploration of connections between code families allowed for a fuller investigation, and ultimately helped to produce a grounded theory which makes a statement about how through people's dynamic and active ideas of identity, the social and culturally embedded experience of type 2 diabetes is mediated by participants 'resistance' to passive conceptualisations of South Asian type 2 diabetics. These 'resistances', which are abstracted from lower level codes are articulated in their actions in diabetes management, the use of syncretic methods, the negotiation of ethnic identity, and connections to places and people overseas for the transfer of both knowledge and products related to diabetes.

The process of coding had been discussed in qualitative literature and with reference to grounded theory frameworks there are a number of positions that have been taken. These positions reflect particular styles of operating and pay attention to specific details of interpretive paradigm preferences. For example, though there is more or less complete agreement that qualitative analysis requires at least an initial phase of coding followed by a more focused phase, there is less agreement about extended and more advanced issues of coding such as axial coding and theoretical coding. While the initial and focused coding phases refer to sufficient analytical sophistication to produce a grounded theory, axial coding is proposed by Strauss and Corbin (1990) as a way of relating categories to sub-categories, and as Charmaz states, “specifies the properties and dimensions of a category” (2006:60). The purpose of this advanced process is to re-integrate the data which have been split by the early stages of analysis and so establishing that there are relationships between different levels and dimensions of a data occurrence. Although some empirical studies may generate research questions and data which warrant such analysis, this was not the case here. Working with a preset framework in order to organise data in terms of relationships between categories did not fit into the analytical method here. Rather, as Charmaz (2006) argues it is possible to follow the leads provided by the data and emergent themes while exploring connections. In addition Kelle (2005) has questioned the
value of axial coding; the jury on this issue seems to still to be out, depending on the needs of the analysis and the particular epistemology of the researcher.

‘Theoretical coding’ is defined as performing a similar function to axial coding in that it allows for relationships to be discerned between categories and the codes produced during focused coding. I did not feel it necessary to carry this out, especially in light of Glaser’s (1978 cited in Kelle 2005) eighteen theoretical coding families which house analytic categories; it simply did not appear relevant or practical. Given that there was already a robust coding practice in place which yielded interesting first order ideas which were connected to higher level concepts, it was an analytical and strategic decision to continue this way.

It should be noted however that the previous two examples illustrate what types of coding have not been carried out explicitly. There is evidence in the coding and overall analysis procedure within this study that actually connections were made between levels of category, and relationships between them were explored as a tool to integrate the findings and move towards the ‘coherence’ aimed at by Strauss and Corbin (1990). In addition to this with reference to ‘theoretical coding’, although this was not explicitly carried out there was a constant weaving together of ideas which were borne of focused coding. These formed a thematic thread to a coherent story of the phenomenon – which in this case was the experiences of people with type 2 diabetes. Typically with techniques associated with grounded theory there is debate and contestation about what is valid and invalid; within this study it was decided that a more fruitful approach would be to maintain a connection with the data; carry out initial open coding; creating groups or families (a term also used in Atlas.ti® V5.0) through focused coding – which would house the sub codes; explore linkages between these families where it seemed apparent and investigate the connections between the codes which were nested within the same families. The sense in which coding, analysis and theorising were kept transparent, technically ‘clutter free’, and grounded in people’s accounts helped to avoid being side tracked by debates occurring on the important but peripheral edges of the debate.
2.3.4 Generalisability

The main findings which are presented in the following chapters illustrate three main areas of focus which help to answer the research questions. Briefly, the first looks at the process of diagnosis, routine management, nutrition, exercise and the monitoring of type 2 diabetes. The second focuses on the types of remedies people in this sample used – typically it was a combination of allopathic and herbal remedies as well as elements of traditional Ayurvedic knowledge. The third looks at the ways in which notions of community, cultural and ethnic identity are interwoven into people’s experiences of migration and settling, as well as their histories before arriving in the UK, and the connection to health and illness. These three sections of findings are evidenced in the transcripts of interviews, the fieldwork carried out in three locations, as well as the interactions which took place in people’s homes. The findings chapters will indicate what these data tell us, but the question about generalisability does raise its head. As already established in qualitative research there is little need to discuss the type of generalisation applied to quantitative studies, but there is still a need to ask the question – does it relate to processes and structures outside of the context of the study? Can this methodology and the findings generated herein be applied elsewhere? The ‘stance’ taken here is line with Mason (1996) who argues it is not enough to talk of idiosyncratic findings, but that there is a strong need to relate findings to a wider process.

While it cannot be representativeness that is argued for, there is a case to be made for linking the methodological processes and implications to wider forces and structures, such that it is possible to connect what happened in this study – in the interviews and other fieldwork – to other places where there are parallel but not necessarily similar set ups. This is not with the intention of repeating the study to replicate findings, though that might have its pros and cons. Rather these processes that were identified in talk and actions, have a much wider resonance with issues of health, illness, identity and culture, and can be pursued and explored in other settings. Herein lays the ‘generalisability’ framework in the study – that actually, as Alasuutari (1995)
succinctly argues, it is extrapolation that needs to be carried out, for this is what relates the analysis and our findings to elements outside of and beyond the immediate study. The final discussion chapter will develop this in more detail.

2.4 THE RESEARCH PARTICIPANTS

Below is a table which summarises participant characteristics and is followed by brief commentaries about each person. They should be seen as a supplement to the existing qualitative analysis throughout this study. It should also be noted that the study has not been restricted to data solely in these interviews but has also been informed by numerous interactions and informal ‘interview’ situations – many of which were spontaneous and therefore did not allow for accurate recording, but still informed the study.

Table 1: Participant details

<table>
<thead>
<tr>
<th>Name</th>
<th>Location</th>
<th>Age</th>
<th>Gender</th>
<th>Length of time with diabetes (years)</th>
<th>Work: Current and previous status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dhansuk</td>
<td>Birmingham</td>
<td>54</td>
<td>M</td>
<td>6</td>
<td>Employed, local council</td>
</tr>
<tr>
<td>Jagan</td>
<td>Birmingham</td>
<td>58</td>
<td>M</td>
<td>5</td>
<td>Retired, self employed in retail</td>
</tr>
<tr>
<td>Sunita</td>
<td>Birmingham</td>
<td>70</td>
<td>F</td>
<td>8</td>
<td>Retired housewife</td>
</tr>
<tr>
<td>Deena</td>
<td>Birmingham</td>
<td>70</td>
<td>F</td>
<td>6</td>
<td>Retired, factory employee</td>
</tr>
<tr>
<td>Sushila</td>
<td>Birmingham</td>
<td>45</td>
<td>F</td>
<td>3</td>
<td>Factory employee</td>
</tr>
<tr>
<td>Rina</td>
<td>Leicester</td>
<td>40</td>
<td>F</td>
<td>3</td>
<td>Employed, South Asian association</td>
</tr>
<tr>
<td>Naresh</td>
<td>Birmingham</td>
<td>72</td>
<td>M</td>
<td>6</td>
<td>Retired, local council</td>
</tr>
<tr>
<td>Name</td>
<td>Location</td>
<td>Age</td>
<td>Gender</td>
<td>Length of time with diabetes (years)</td>
<td>Work: Current and previous status</td>
</tr>
<tr>
<td>---------</td>
<td>------------</td>
<td>-----</td>
<td>--------</td>
<td>-----------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Harish</td>
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<td>74</td>
<td>M</td>
<td>20</td>
<td>Retired, postal worker</td>
</tr>
<tr>
<td>Kanti</td>
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<td>F</td>
<td>18</td>
<td>Retired, Volunteer worker</td>
</tr>
<tr>
<td>Bikhu</td>
<td>Crawley</td>
<td>58</td>
<td>M</td>
<td>5</td>
<td>Retired, self employed in wholesale</td>
</tr>
<tr>
<td>Basanti</td>
<td>Crawley</td>
<td>65</td>
<td>F</td>
<td>6</td>
<td>Retired, housewife</td>
</tr>
<tr>
<td>Pramod</td>
<td>Preston</td>
<td>59</td>
<td>M</td>
<td>15</td>
<td>Retired, factory employee</td>
</tr>
<tr>
<td>Bharti</td>
<td>Preston</td>
<td>54</td>
<td>F</td>
<td>8</td>
<td>Housewife</td>
</tr>
<tr>
<td>Preeti</td>
<td>Birmingham</td>
<td>56</td>
<td>F</td>
<td>1.5</td>
<td>Housewife</td>
</tr>
<tr>
<td>Basanti</td>
<td>Crawley</td>
<td>65</td>
<td>F</td>
<td>6</td>
<td>Retired, housewife</td>
</tr>
<tr>
<td>Pramod</td>
<td>Preston</td>
<td>59</td>
<td>M</td>
<td>15</td>
<td>Retired, factory employee</td>
</tr>
<tr>
<td>Hasmukh</td>
<td>Leicester</td>
<td>53</td>
<td>M</td>
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<td>Self employed in catering business</td>
</tr>
<tr>
<td>Nilesh</td>
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<td>51</td>
<td>M</td>
<td>28</td>
<td>Communications worker</td>
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<tr>
<td>Rajesh</td>
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<td>M</td>
<td>6</td>
<td>Local council</td>
</tr>
<tr>
<td>Kishore</td>
<td>Leicester</td>
<td>59</td>
<td>M</td>
<td>25</td>
<td>Self employed, accountancy</td>
</tr>
</tbody>
</table>

Note: In total there were 20 interview participants; 1 interview was on the whole inaudible, and 1 interview was incomplete during recording and therefore generated limited responses.

**Dhansuk**

The interview with Dhansuk was set up through my field contact, who was known to him from previous engagements, and took place at the workplace/home of my
contact. Dhansuk arrived on time and seemed happy to carry out the interview. As elaborated elsewhere, although we were relative strangers, having only spoken on the phone once before, some 2 weeks previous to the interview, there was an element of pre-recognition, due to our paths crossing some 10 years earlier. He has been actively involved in the Gujarati community for many years in the UK, and holds a prominent position both as a council member and within his status in community relations. In the interview he is comfortable, relaxed, and appears to have a familiarity with speaking about diabetes; the interview reveals that he has completed one of the government health initiatives in the Expert Patient programmes with specific reference to diabetes.

Jagan

Jagan is a retired business man living in a socio-economically advantaged area of the city, in a large house. He lives there with his wife and children. He is happy to be interviewed and since I arrive earlier than the arranged time I have a conversation with his wife, who offers me drinks and a snack. The ritual of food / drink offering is a common and consistent one, and while not culturally distinct, offers up some particular research related issues. The concept of the 'research interview' itself is not a familiar one with many people, and of course ethnicity does not necessarily play a part in this. However, the organisation of the interview can be difficult, especially if the other people in the household are not aware that the interview is only with the one person. This was the case here, and I asked if there was somewhere quite we could go to, or if he was comfortable there – we went to the dining room where we had privacy. The interview itself was a satisfying one, although many issues were raised which created some difficulties. Jagan had been experiencing forms of depression and had suffered from extreme anxieties – the specifics I was not in a position to enquire about. The concern in the interview was that he was comfortable talking to me, and he was empowered enough to stop if he wanted to. This seemed to be the case, and no risks were apparent. He talked at great length about not just the diabetes but more so the other troubles in his life, and how the diabetes was an additional health issue he had to deal with. Given he had been self employed and had sold his business to retire, he had found himself in a comfortable financial position; he told me that he had had a
home fitness gym built, where he and the family could take exercise, sometimes together. Throughout the interview (my tape recorder had malfunctioned) I had been taking notes, and realised that this often distracted both of us. The propensity to write down every detail in case it was important for the research seem to override the requirement to be engaged socially and emotionally. A decision was made to make only key point notes, key words which would hopefully after the interview allow me to re-construct some of the details of the conversation. This reengagement resulted in Jagan immediately talking more openly, and certainly appearance wise looking more comfortable. The interview was stopped several times when his wife came in to offer more drinks and snacks.

Sunita
Sunita an elderly widow living on her own (her age was not available but estimated at 70) was recruited to the sample during my first trip to one of the community centres in Birmingham. After arranging a suitable time for the interview I visited her at her house. She lived in a city area of Birmingham on the main road. I was met with warmth and openness, and she showed me into the second room of a two bed roomed terrace. The second room had been turned into her sleeping quarters, as she had trouble getting up and down the stairs frequently. The walls were adorned with religious pictures, and in place in the room there was a small shrine and worship area. I sat on a sofa, while she sat on the end of the bed, and began the interview. Sunita was very open and talked freely, although she was quite troubled by interactions with her neighbour, who had been acting aggressively lately. This presented troublesome ethical and moral dilemmas for the research, which have been discussed elsewhere. Since she lived on her own, she was a little worried about her safety, though when she spoke of anxieties and risks in life, she would glance at her religious pictures and talk about how her faith in God would keep her safe. She also got up to show me all her prescribed medication at one point — this was a common feature of many of the interviews — the misconception that I was there to ‘assess’ them in some way, or that as a medical professional I could offer medical advice. As part of the research process I did not reject a participant’s need to show me medication — I would firstly clearly
indicate that this was not necessary, and if the participant proceeded, I took this to be a
decision made of free will. Ultimately, showing me their medication may have
served a positive function for both them and the interview; perhaps increased rapport;
perhaps self-assurance that they have disclosed the ‘legitimate’ nature of their
medication concordance; or perhaps simply the gesture of sharing information. When
the interview ended, Sunita showed me out and as we walked back through the front
room, she stopped and showed pictures of her husband and family, where we had a
detailed discussion of my family background, upbringing, history in India etc before I
left.

**Deena**

Deena was a widow who lived with her son. As with all the participants, she was
warm and friendly and greeted me with the colloquial ‘brother’ terms in Gujarati.
Again she was open and talked freely — and at one point when she was talking about
her early experiences of racism she asked me if it was acceptable to talk about things
other than diabetes. She described a great many things about her diabetes routines,
herbal remedies, but also her migration experiences, and her role in the community.
She had also worked as a teacher in India for 40 years, before arriving in the UK,
where she played many roles in local voluntary and charity work. Having been
widowed when her son was young, and experiencing many negative incidents meant
that they had moved frequently since arriving in the UK from Kenya. The place where
she and her son now lived was as she told me a safe and quite place. The interview
took place in her living room, and halfway through she insisted on bringing snacks,
which she wanted to prepare fresh. As she went and did this in the kitchen, she
dropped a bottle of oil which broke. I helped to clean this up with cloths and a mop,
and as we did this she proceeded to talk about many things. The tape recorder was not
in the same room and was switched off. Although this interaction was interesting and
provided context, it was not recorded and constituted more of a social interaction than
a research sound bite, and has been treated accordingly.

**Sushila**
This interview took place at the participant’s home, and was conducted with a female relative present. Sushila was obliging in agreeing to talk with me, but since we had never met before, felt more uncomfortable without a third person present. She had had type 2 diabetes for 3 years, and both of her parents had suffered with the same condition. The interview was conducted in Gujarati as this was the more familiar language, but there also seemed to be a gendered relation at play; Sushila was very quiet, shy and retiring, and responded to queries with either short answers or a smile. Many times in the interview she would look to the other person in the room before responding, and upon approval would then answer. The third person in the room was fluent in English and Gujarati, and displayed both a confidence to interact with me and a protective attitude to Sushila. This was encouraging in the sense that it provided support for the interviewee, but discouraging because there was little ‘flow’ or rapport to the situation. However, there was no sense of animosity and so Sushila did try and answer the queries to the best of her ability. There were no other distinguishing features of the interview, and many of the themes common to the other interviews also emerged here, such as use of herbal remedies from India and exercise and nutrition.

Rina

Given that most of the sample in this study were Hindu Gujarati elders who had type 2 diabetes, Rina was a deviant case in that she was a type 1 diabetic and relatively young in comparison at 40. Although the nature of the conditions differ in many respects, there are certain similarities in the experience of condition management. This participant was comfortable talking about her early experiences with the illness – before and after she was diagnosed with type 2 diabetes (her condition later progressed to type 1), and many of her reports and expressions had commonalities with other type 2 participants. Although it would have been possible to withdraw on the basis of failure to meet research criteria given the interview had not really started – it was also not possible because social interaction had started. The other distinguishing feature about this interview was the presence of her mother, who was present throughout the entire interview. I was welcomed into the family home, and offered refreshments. As the interview began it was apparent that the mother was
going to stay. This was assumed to be out of social and cultural etiquette, given I was a stranger, and male, talking to a single female in a relatively intimate and isolated environment. Rather than take this to be a confounder of some type, I treated this as an interactional result of the encounter, another source of data, and indeed as the interview progressed, the mother did make significant contributions. As discussed elsewhere in this study, health and illness are not experienced in isolation from other people, but rather in collaboration with others – who may be family, friends or other forms of contact. The process of illness management then was undertaken by all concerned, and here this included the participant’s mother, especially since it was her pressure on her daughter which had led to the diagnosis. The problems of disclosure and stigma as well as other issues of life changes such as family bereavement were revealed in this interview, as context providers for the management and dealing with of diabetes. They were also both heavily involved in work within the community.

Naresh

As with many others, the interview took place in the family home, and again as above the presence of a third person was accepted as taken for granted. Naresh’s wife was present for some of the interview, and some time into it his daughter-in-law and grandchildren were also present (though obviously not in the interview – the tape recorder had been stopped). There were no peculiar characteristics to this interview, other than the participant was open and friendly.

This was an interesting interview, in that the respondent was very keen to talk to me. As before, his wife was also present. Both were friendly and cooperative, and interested in the study I had told them about. As before, they were interested in me, my identity, who I was, where I was from, which village in India, Africa, which family name etc, and when I demonstrated both a fluency in the language and familiarity and knowledge of the Indian subcontinent, the gentleman was very happy to talk in detail.

Harish
The interview with Harish came about through snowball sampling, and was the result of the contact with Naresh. Again I visited the home and interviewed there, and as before the wife of Naresh was present. Harish was open and friendly, though initially many of his responses were polite but short. He would respond to probing, though there were issues he was less willing to talk about. Rather than pressure him we engaged in tea and some snacks, whereby he became much more open and talkative. Even after I had turned the tape recorder back on he continued to talk in some detail. The characteristic features of this interview were Harish’s connection to his biographical history, and his somewhat steadfast refusal to be bound up in the politics of local communities. Whenever his response was short and enigmatic and/or ambiguous I would probe further. Harish’s interview yielded important data concerning community, identity, life experience, self assurance and independence and a variety of other issues.

Kanti

The contact that had facilitated access to the first site visit had also provided the link to Kanti, an 88 year old widow who had arrived in the UK in 1987. She has been a very active in the field of South Asian community relations in Britain for many years, and was still very active. I was told she had type 2 diabetes, and was happy to talk with me. I called this woman, and she was very open and warm, and kindly agreed to my visiting the centre / temple to talk with her and other people there. The connection to Kanti was two fold – firstly as a potential interviewee, and secondly as another gatekeeper to the research site. Although the telephone call was brief and introductory, while we were on the phone, she also told me she noticed my accent (we spoke Gujarati) ascertained where I/ my parents might be from. From there she went on to tell me where she was from, and from this various levels of familiarity were established, serving to increase rapport. As a local leader and someone holding a position of respect as an elder and community activist, Kanti was held in high regard, something evident on the day I arrived at the temple to meet with her and others. This is outlined in another section. The interview with Kanti took place at her home on the same day as my visit. Again she was happy to talk about many aspects of her life, and
needed very little prompting or probing. She was very clear about the purpose of the interview, and it seemed her knowledge and experience provided a basis from which we could both explore her story. The interview was characterised by themes of endurance, tenacity, and adaptation, mediated by coping frameworks such as religion and faith, training, life experience and devotion to duty. Although she was clear about the research being diabetes related, she was also clear about my interest in learning about her story, and her experiences, since her talk is peppered with contextual material ranging from adverse experiences such as burglaries and attacks, to positive experiences of helping charities with donations. She constantly provided explanations for her answers to my questions, and so the interview situation was not fraught with any particular silences or difficulties.

**Bikhu and Basanti**
The interviews with Bikhu and Basanti took place in the same home, and at the same time. This procedure of not splitting participants up is one already described and discussed in the Method section, and rather than seen as a possible confounder or problematic, is regarded as an interactional outcome inherent in this research.

They are both retired, and though the interview was initially supposed to be with Bikhu, it was revealed that his wife was also a borderline type 2 diabetic. In a previous meeting we had also talked at some length about herbal remedies, the management of illness in the family, and so their suitability was established prior to the interview. They live in an extended family setting with one of their sons, daughter-in-law and two grandchildren. Because of my familiarity with them there is little need to build rapport, nor to initiate much of a ‘grand tour’ (Spradley 1980: 81), although as is usual the interview started with basic queries. Bikhu had had type 2 diabetes for five years, had also suffered a series of heart complaints (angioplasty), and was currently wrestling with a weight problem. Basanti was more experienced in diabetes and illness management – and was fluent in the expression of health and illness states. They both were willing participants and actually started talking before the tape recorder was switched on. This early part of the interview focused on
migration, life histories, and settlement. The outcome of the interview may have been different had I conducted the interviews separately, but given that these are “guided conversations” (Burgess 1988), and the problematic and contested nature of the word ‘interview’, my judgement was to continue and realise the potential of having a three way interaction.

**Pramod and Bharti**

Unlike the situation with Mr. and Basanti, I was fully aware that both of these participants were type 2 diabetics. They were both familiar to me through informal connections, and so establishing a rapport over a period of time was not an issue. Initially, I did specify that I would interview them one by one, but they both decided they would be interviewed together. For the reasons already outlined, this was acceptable in the interview and it proceeded. When I asked Bharti if we could begin, she indicated that her husband was also diabetic, and that he would also be happy to talk. It appeared that she would be more comfortable in his presence, even though I was a ‘familiar’. They both lived in the same house, a moderately sized semi-detached house, with their daughter. Their other children had moved away after marriages. As with all the interviews, they were open and friendly, and it was evident that this interview was going to be a ‘team effort’. Even though they both had distinct roles in the house, separate experiences of diabetes and health management, they also had interconnected experiences, and these were related to some of the questions in the research. Another common element of many of the interviews was that regardless of their concept of ‘research’ and the role they or the study would play in diabetes, they felt they were contributing in some way and therefore were happy to help.

**Preeti**

On the same day as my visit to the second site where I was able to speak with Kanti, I was also able to arrange an interview with Preeti, which took place the next day. She was uncomfortable with the idea of having the interview in her home, or of it being tape recorded. We met the next day at the temple and I waited for her to finish her morning prayers (at the place of worship upstairs). Since the interview was to take
place there, there were certain problems that were unavoidable. The other attendees at
the centre were getting ready for an exercise class, which was happening in the middle
of the room, where a gentleman who greeted me warmly earlier sat, with chairs in
front of him. Preeti and I found a table where we could sit and talk, hopefully out of
reach of any interference. Again I asked if I could tape record the interview and again
she smiled shyly but was clearly uncomfortable. I started the interview and needed to
take copious notes – as she was a rapid speaker. This combined with the exercise class
created a problematic research situation. The interview was limited by not having a
recording of the talk, although the notes taken during the interview indicated that
there was little which deviated from the consistent categories and themes which have
emerged from the other interviews. One of the interesting themes that emerged from
Preeti’s interview was her comments on the lack of unity in the Hindu community,
and the contrast to the Muslim community, where divisions of caste etc are not
common. This from her perspective resulted in differential treatment within
communities of the sick and vulnerable. Preeti was overall open and friendly, but
indicated an underlying tone of anxiety concerning her role in the interview –
although she was more than happy to sign the informed consent form.

Hasmukh

Hasmukh is a self-employed caterer, married with children and has had type 2
diabetes for at least several years. The precise length of time is unavailable due to
poor tape quality. The interview was conducted at his place of business in his office,
although it was quite and private. We had not met previous to this and so part of the
time spent there was in building rapport and talk of a general nature. Although there
were few outlying or significantly different features of this interview, Hasmukh
interestingly talked about ways in which he moderated his medication in line with his
nutritional intake, as well as taking herbal remedies from overseas. As with many
other participants there was also a common theme of either having or not having the
opportunity of ‘sweating it out’ through exercise. Hasmukh told me the work he
carries out in his catering business means that he does hot and sweaty work much of
the time. However since he was diagnosed he had also initiated a daily walking ritual with his friend who calls by his workplace once a day.

Nilesh
This interview, along with Rajesh and Kishore was sourced and conducted at a community gathering in Leicester focusing on a visit from a spiritual figure from India. Nilesh was amongst a large number of people occupying various roles during the event. Although I had specified that I was carrying out research on type 2 diabetes (I would also mention this was ‘the tablet and diet related diabetes’ as this always served to clarify any confusion), I was directed to Nilesh, and only found out after I had started the interview he was type 1. However, for the same reasons outlined earlier for Rina it seemed unethical, impractical and analytically and empirically short sighted to stop the interview, so it continued. Nilesh was open and friendly, and although was taking some time away from his duties was still clearly a busy man. He had had diabetes for 28 years – the longest length of time of the entire sample, so was clearly fluent in the physical, practical and social impacts of the condition. Much of his talk was centred around the use of insulin and the physicality of injections which did not apply to the study, nor the other participants. However, there were interesting and relevant common threads such as the use of Yoga as an exercise, mediating calorific intake during social events, and the stigma experienced by family and specifically parents when their child is unmarried but has the condition.

Rajesh
Rajesh as with the other two participants from this site, were carrying out assisting roles at the event, and though they were busy with the event, which held an estimated ten thousand people that day, they were all happy to talk with me. The access to both this site and these participants was again through a contact in the community who was also playing a role in the event. With his recognition and validation I was able to gain unfettered access to the event and people. Rajesh was comfortable speaking with me, although he was clearly in the middle of a busy period and combined with outside
noise concentration for both of us was affected. He responded to most of my queries, however open ended with polite but short answers, and although he seemed comfortable I was aware that this physical space was not ideal for him.

Kishore
As part of a trio of participants (all male) who were recruited at an event in Leicester Kishore was clearly fluent and eager to talk with me about a range of topics related to diabetes. He volunterred to go last, indicating that he may have more to say than the others, and was willing to wait for them to finish. Like the others he was helping in this community event, and felt it was a role that was necessary for the fulfilment of community cohesion. Before we started the interview he asked me if we were going to talk about the medical or the social aspects of diabetes, and I replied we could talk about either of those, depending on his choice, and then went on to explain the purposes of the research. He did not require much probing or querying, and was happy to talk both about general aspects of diabetes and quite specific related topics. He talked in detail about how the South Asian community could benefit from a different approach to health education, and offered a series of interesting metaphors that he himself used frequently when talking to people (these are discussed in the findings section). He was clearly well versed in the details of type 2 diabetes, but also went on to elaborate the emotional impacts on families. It is unclear whether he was using the interview to instruct me on how the community could benefit from a different approach, or whether he was buffering and contextualising his own specific experiences through relating to the general discussion; regardless of this, he was open and friendly, and willing to help.

This chapter has provided an account of the overall method utilised in generating findings in this study, paying particular attention to the way in which qualitative methodology is most suitable for this research. It has also provided details of the participants and brief commentaries which function as profiles about the people interviewed. The following chapter discusses in more detail the proccessual and
dynamic nature of identity interconnections, and the role cultural identity (of the researcher and the participants) has played in the overall study.
CHAPTER 3

LOCATING THE ROLES OF PARTICIPANTS AND RESEARCHER
THROUGH THE PROCESS OF “CULTURAL VALIDATIONS”

Introduction

This chapter discusses an intimate relationship between how the data is generated, and what the data might tell us about the social phenomena. This inherent relationship between theory and method, and between method and findings is not new of course (Fielding 1986), but certainly within this study, there is interesting information to be gleaned. The use of 20 qualitative semi-structured interviews, combined with a range of ethnographic sessions and my experience with the participants, gave rise to the idea of ‘cultural validations’.

The interactions which took place in this study were the coming together of identities, linked by language, dialect, accent, history, biography and connections related to ethnic belonging and identity. I argue here that it is precisely through these ‘cultural validations’ that I was able to gain access to the participants, and which generated both a richness and particular content in the data. The identities of all participants in the research will interconnect at a variety of levels - psychologically, emotionally, socially and symbolically.

This section will provide an account of how these validation processes occurred, using some highlighted texts from interviews, and field observations in the attempt to explain the interconnected nature of identities in research.

I was assessed at a variety of different points in the study process, including during a telephone conversation which established my dialect, which in turn indicated to the respondent which part of Gujarat I may have originated from; being quizzed about my family surname; my parents home village in India; my caste affiliation; the business
or profession of my father; my marital status and my language abilities (established very quickly by speaking in the language and gauging my linguistic response). My responses in each of these situations (which occurred both in private homes and in community centres and temples) would be the evidence each ‘gatekeeper’ and / or potential participant would use to decide whether or not an interview would be granted, and perhaps more importantly, the depths to which our interaction might or might not reach.

It is then the role of qualitative, in-depth sociology to ensure these identity interactions, which may be a product of or the generator of ‘cultural validations’, are allowed to inform the analysis of the data and the findings in general. This has a particular resonance for the study of health and ethnicity, where the roles and ‘ethnicities’ of researchers have been the subject of much scrutiny (Song and Parker 1995, Ladson-Billing 2003). While the debate continues, it can be argued that we can harness the concept of ‘cultural validations’ and facilitate an environment conducive for the generation of rich, situated and interactional data. These articulations — people’s voices — can be seen to demonstrate more than simply health choices — as the data will show — they demonstrate a wide range of social action related to health, illness and ethnicity.

The combination of researcher identity and social research for the purposes of exploring social and cultural worlds is not new. Feminist researchers (Stanley and Wise 1993) and critical race theorists (Ladson-Billings 2003) have already explored how identities of all concerned shape research and are mediated by power relations; as Ladson-Billings states: “my research is a part of my life and my life is a part of my research” (2003: 417). While I cannot not necessarily invoke a sentiment of this power within this study, nor do justice to Ladson-Billings’ embodied research, it is possible to connect with the essence of her argument through the concept of cultural validations. The overt and explicit acknowledgement of researcher biography connecting with aspects of the participant identity facilitates a reflexive qualitative methodology. Through a series of cultural validations a picture of how type 2 diabetes
is socially and culturally embedded could emerge. The Methodological framework allowed the generation of data which pointed towards participants demonstrating that what they did with diabetes in their lives was far from an acceptance of passive identities; that there was an active formulation of cultural and ethnic identity emerging from social action, and this represented a form of what I have articulated as 'resistance' to health and ethnicity discourse driven notions of ‘South Asian diabetes risk’. The theoretical strands to this are discussed later.

3.1 Identity work

If we accept the situated nature of data generation and the very social interactional character of the research process, then we also subscribe to what Coffey (1999) described as the physical and embodied experience of fieldwork. For Coffey, “fieldwork is personal, emotional and identity work” (1999: 1), and requires an acknowledgement that one needs to go beyond describing and explaining social phenomena. Rather one needs to explicitly engage with one’s location physically and socially, so that the phenomena observed and engaged with are contextualised by the interaction of bodies, personalities and socialities.

This idea of identity work, briefly discussed above is not a bolt-on manifestation of late modern reflexivity, serving the purpose of tokenism so that an appearance of identity reflexivity is created. Rather it is more a constantly interwoven thread throughout the study, having an impact on the nature of the planning and engagement in the field, and the nature of both the findings and their interpretation. This section has been labelled ‘cultural validations’ precisely for this reason; that throughout the study, gaining access, interacting, interviewing, socialising, observing and being accepted or rejected, were all contingent on a series of validations brought about within the study. These validations were not static expressions of acceptance or rejection, but instead – rather like the nature of the chronic conditions such as diabetes – are processual and changing, therefore contingent on interactional forces. The epistemological base on which this study rests is an explicit acknowledgement that
there are both pre-existing and newly formed connections between the researcher and researched which facilitate and shape the nature of the research.

The concept of cultural validations describes the epistemological stance taken in this study, which is the acknowledgement that there are connections which take place between the researchers and researched which go beyond language and basic communication. This stance also integrates the possibility that there are also points of departure between the interacting entities in social research, and that difference and similarities will exist. The stance makes explicit these points of connection and helps to explore how they impact the work that is done by both researcher and researched. As Coffey (1999) states, one of the advantages of getting involved in the field is this in-depth engagement and the resulting reflexive discussion of what that means.

The processual nature of the methodology in this study reflects both what Coffey has called the relationship between “position, place and identity” (1999: 36), and what Mason has called “relationship work” (2002: 93) and “identity work” (2002: 94). The role of my cultural background and history, including family history, migration trajectory, position and settlement pattern in the UK, ability to converse fluently in Gujarati, and familiarity with a range of common social and cultural identity markers, facilitated both my access to people, and the kinds of things they talked to me about. These will be discussed in relation to the fieldwork below.

3.2 The offer of tea – a symbolic identity marker?

Further to the point made earlier regarding socially and culturally situated markers, an example which may illustrate the point is the otherwise simple task of responding to the offer of tea or refreshment. Tea in many South Asian communities holds a universe of varieties of both tea leaf and the way in which it is prepared. The common factor is that it is prepared using a range of spices, and almost always boiled with milk. The offering of this type of prepared tea is in particular a cultural and ethnic marker of identity – shared in households globally, with variations on a theme. When
a refreshment and/or tea is offered, there is ostensibly a choice to be made. One could take or leave the tea. However, to know that tea is made a certain way, and to request it in this way — is demonstrating both knowledge and experience of something that is shared. Of course, this is a post-event deconstruction — at the time the action was automatic simply because my personal preference and taste also happen to connect with that of others. The indication that tells us something symbolic happened when this choice was made was in the attitude and response to my choice — as soon as I requested a particular type of tea, emphasising that I did not want to inconvenience them, there was a positive response: “well, that’s exactly what we have so it’s no bother! Oh yes, we do like our masala chai!”

Rather than dismiss these interactions as part and parcel of ‘normal’ and expected ethnographic work, one might contend that they are powerful expressions of cultural validation — not limited to ethnicity, but powered by an expression of or facet of it. The resonance of something as seemingly straightforward as my preference for a tea to be prepared a particular way, is a strong validation, and assembles, along with my linguistic and cultural references, a comfort zone. Approval from within the subjectivity of social action and not from above or outside it is granted.

3.3 ‘Authenticity’

There is a risk of supporting an essentialised notion of ‘authenticity’, or ‘sameness’ which links the researcher/researched entities. This is certainly not the intention here as this process of cultural validations is precisely that — pro cessual — and therefore contingent on dynamic cultural processes, albeit given a hand by existing points of commonality shared by the people involved. This study looks towards a negotiated order of identity which is constructed on both sides of the researcher/research divide.

Within the study it was not just linguistic abilities that allowed access into ‘cultural domains’ but all the constituents of cultural frame-making, such as familiarity with linguistic, religious and cultural nuances, as well as familiarity with history and
geographical location. In addition there was the added element of a shared migration experience. This points towards a process of connecting through various cultural mechanisms which moves beyond static notions of race and ethnicity, and which works through 'linkages' in biographies, via migration and family histories, diasporic histories, caste and community affiliations, and the linking of cultural frames of reference. It is not argued here that without these linkages the research would be invalid, or that the same richness would not be present. To do so would bring the debate full circle into the quagmire of 'same-ness' which is trying to be evaded. It is a cultural constitution which takes its thrust from the negotiating of symbolic markers of difference, and as a social process it is also contingent and sometimes fragile, but always able to be both firm and flexible. This was aptly demonstrated by participants staking their claim to question my 'appropriateness' through questions about my family name, history, migration trajectory, as well as my ability to respond and interact in the chosen language.

It is through this epistemological lens that social action is characterised, observed and collaborated in, so that the ontological base on which the study sits also reflects the way in which insights about the experience of type 2 diabetes in Gujaratis can be gleaned.

3.4 Connections, mistaken identities

On several occasions during the study a series of familiarities and coincidences occurred which proved both interesting and fruitful. On the first occasion during a telephone call to the first potential participant, it was revealed in the call that we had met many years previously, and that he was familiar with my family, though there had not been contact for some time. The nature of this existing relationship was quite formal, as he played an important role in the national organising committee which represented the caste of this group of Gujaratis, of which my family is a member. This point of familiarity functioned as a ‘foot-in-the-door’, and may have eased access to this participant. Although there was no apparent negative impact on the interview of
this familiarity (gauged by length of responses, rapport, tone of voice and general cooperation), it is certainly feasible that I missed an ‘effect’ or artefact of this dynamic.

The second occasion where inadvertent familiarity played a role rather unexpectedly was during a case of mistaken identity based on my family surname. During a field visit to one of the temples / community centres, while I was talking to one of the potential informants the council leader approached us, and told the informant who I was the son of (in English this would be more appropriately translated as “informed him of my father’s name – however in translation it loses its culturally specific semantic weight). The potential informant then proceeded to speak to me in rather harsh tones, and demonstrated that there was an obviously contentious relationship between these gentlemen and my father. At this point, I became aware of the downside of familiarity – that while endorsements may get you into a situation or group, all of these interactions are resting on and driven by fragile historical legacies, reinforced by memories, some accurate and some not. I enquired further, and it was revealed that I and my father had been mistaken for someone else. On further elaboration of roots and origins and family specifics, (and many apologies later) the council leader then animatedly told me he knew my parents and grandparents, and in fact had lived in the same street with these people and recalled these memories fondly. The status of the relationship was then quite fragile, but also once repaired by communication, the access gained was far greater than had the error not occurred at all. Through connecting my grandparents’ location to the people at the site, there was an opportunity to demonstrate some sense of ‘legitimacy’; perhaps this can also be called showing a common stake in the project. The council leader asked me to step to the side, where a process of further validating occurred in Gujarati (questions about the research, where I was based, further questions about my family). After this process I assumed (avoiding the assumption that these validations can ever be complete) that my role or at least my presence was given some validity.
A third case whereby a form of screening and subsequent validating took place was entirely over a telephone line. I had called a potential participant who had been informed of my details and that they should expect a call from me. As I spoke to her in Gujarati she immediately told me that she knew I was from a certain region in Gujarat — or at least that my parents were from there (and had passed on their linguistic dialect and accent to me). She then went on to tell me where she was from, and having history in East Africa as most of the people in this study (including myself) we talked about this for some time. Even though for a fluent and experienced speaker it is not always difficult to discern differences in origin, the connection that had been made through a dialect nuance was a useful tool for both parties — for her it provided a sense of ‘knowing’, perhaps an expert knowledge status which could be useful for relations during our interaction; for me it provided a ‘way in’ to the interaction, and formed a basis on which I could then work.

These cases offer an insight into exactly how this process of cultural validations can work, and are important as illustrative examples, lest the concept lose its empirical and grounded nature. Two final cases briefly illustrate how shared experiences can work in the research setting. Harish was talking to me about their early experiences settling in the UK, and during this time tea and refreshments had also been brought into the room. As we talked — for there was an exchange rather than a question and answer session, some of his responses were short, so I decided to talk about the period in which my family and I had moved to England from Africa. Immediately both he and his wife became animated and though not surprised at the fact itself, went on to discuss how much more difficult it was for them as they had arrived many years before we had, thus revealing deeper experiences than had otherwise been mentioned. This overtly simple sharing allowed a process of validation — in this case it might be cultural, but seemed more akin to experiential validation.

The final example illustrates how being able to move in and out of linguistic nuances performs a useful function. Naresh had been talking about Gujarati food and diet, and methods of cooking, mentioning that many times the way South Asians — here
Gujaratis (it is difficult to be absolutely precise about group membership because of the terms used – “apra ma” – translates to “in ours”, which could mean a range of different things related to religion, culture, caste and ethnicity. For this reason I used South Asian) – cook their food reduces the amount of nutritional content, through a process of initial cooking preparation using oil. This process is called “vaghar” and is common to many Gujarati dishes, performing the function of creating a culinary base on which the dish can be cooked or built. The process of waste, or spoiling matter is called “bagghar”. When Naresh mentioned that using this system of oil based preparation results in spoiling, I interjected with what might be called a rhyming phrase using the two terms above, in Gujarati. The result was a humorous exchange which both Naresh and his wife seemed to appreciate, but more relevantly for this study, demonstrated that they could indeed talk to this researcher about much more than the diabetes experience. Given that the research questions were focused on the socially and culturally embedded nature of type 2 diabetes, this exchange allowed for a wider ranging interview about food, diet, and even global changes affecting villages in India.

Within the context of the study it was not however assumed that this was carte blanche in terms of access and potential participants. It was the result of a particular combination of serendipity and the cultural linkages that could be formed and articulated at that time. It did not constitute any guarantee for the research or my access to individuals. However the point needs to be made that once my presence had been validated by someone and this was seen publicly – e.g. by the other people attending the community centre that day, then they were more likely to speak with me openly and grant an interview.

3.5 “It's ok. He's one of our children”

This local ‘endorsement’ also occurred on other occasions during the study. During another visit to a temple / community centre, I was granted access to the people who were attending, and had the opportunity to speak with someone who was quite active
in the community and therefore keen to facilitate my role and research. Within these community centre settings there is usually a physical gender divide — the men gather on one side and the women on the other. There is interaction between them, but generally only if necessary. The set up acts like a social gathering and forum for South Asian elders to mix, socialise, share lunch, exercise and sometimes listen to a health related talk. As I approached the women to talk to them (having already gained permission from the local leader and several other members), they appeared slightly hesitant to cooperate with me. They may well have been uncertain of what I was doing there, and anxious that I represented an institution or organisation. As I made several attempts to talk to the women, the woman whom I had met earlier came to my side and said: “it’s ok. He’s one of our children. He just wants to talk with you as he’s doing some work on diabetes, so please cooperate”. On receiving this information, the group opened up, appeared much more at ease and I was able to speak with most of them, gaining direct information and from potential participants. Again this points towards the building of identities as negotiated orders, which remain fragile but at the same time flexible. This interaction was also mediated by gender and age — the older South Asian women were more likely to categorise me, a relatively younger person as a ‘son’ figure, and therefore happier to cooperate. This outcome was of course also dependent on the relationship work that had already been carried out (talking with other people, helping to set up tables and chairs, eating lunch with the men) but the common language coupled with an endorsement eased the way and helped to construct a more complete picture of the situation.

The validity of the concept or process of cultural validations as a contextual frame for methodology is illustrated in the way it sometimes did not occur. As well as the case of mistaken identity discussed above, there were other rejections which took place. On more than one occasion when it was explained what the research was exploring (not an easy set of concepts to articulate in two different languages), the response was: “you’re not a doctor; not a medical person. But you want me to talk about my pains and problems. Why?” This comparative familiarity with the medical model and representatives thereof was common in the sample; there was a prevalent familiarity
through the careers of grandchildren or children in medicine, law and finance within this Hindu Gujarati population and although there are connections to be made here, do not fall within the scope of this study. This familiarity and comfort with the medical model was also juxtaposed with the consistent use of both knowledge and products originating in complementary systems of medicine, such as Ayurveda.

One woman who I approached questioned me about my surname (surnames can be an indicator of caste in the Hindu community). I replied with my surname – which is one which does not indicate caste, and the woman not recognising it declined my request. I realised what had happened, that some small in-out group dynamic was being played out. I then stated that I was from a family which had gone through a surname changed through the migration process, and stated the original surname of my family. The women replied “Really? Oh in that case...yes I’m happy to talk with you”, after which she was more than happy to speak. In any case she did not have diabetes so the conversation went no further.

In these cases, the screening, validation and endorsement processes seemed not to yield fruit, and yet this is no more surprising than everyday social interaction outside of the research field, where alliances and friendships are made, unmade or ignored. In one sense, had this cultural validation process demonstrated unequivocal and unquestioned access throughout, then questions would need to be raised about the exact nature of the process and whether there were other processes operating. In a very real sense, the process of cultural validation is as much about rejection as it is about acceptance. In a fashion very much like a ‘validation’ check occurs in other arenas of social life – where entities of sociality are constantly engaged with, talked about, reviewed and then decisions are made about acceptance or rejection – or suspension, so these processes are really about making the routes of these connections explicit.
3.6 ‘Others’ in the interview

Within the research tradition there is a taken for granted assumption that the notion of an ‘interview’, be it research or otherwise, involves two people, and of these only one person will be the ‘subject’. This assumption appears in many forms of research where interviews are required, but within this study, it was an assumption which was questioned time and again. Even where specified and named people were asked to participate in the interview, for a variety of reasons, more than one person would be in the room and sometimes would be part of the interview itself.

The presence of a third person within the interview situation can perhaps be traditionally regarded as problematic, in terms of influencing the respondent, resulting in bias, social / peer pressure, the possibility of impression management (construction of socially / interpersonally sanctioned versions of self), and a variety of elements one might pick out of natural science prescriptions. The arguments pitted against such an occurrence serve to invalidate the presence of a third person, and insinuate that whatever contribution – be it verbal or non verbal, symbolic, psychological or otherwise – they have to make is not part of the interview. Here however, there are three issues which can be discussed to support this additional person’s presence in the interview. Firstly with reference to culture and ethnicity and secondly in relation to the established philosophy of qualitative method. These factors suggest there is an impact on research where there is a combination of both of these – the sociology of health/illness and ethnicity being a prime example.

3.6.1 Culture and ethnicity

Within this study, it was very often the case that there would be someone else in the interview situation with us during the interview. Sometimes this would be a husband or wife, mother, son, or another member of the immediate and / or extended family. While initially this caused a hesitation it soon came to be the norm in this study. I accepted that there were a number of cultural, ethnic, general etiquette and gender
based mediations occurring, sometimes simultaneously. Many of the participants were elderly, and whilst happy in the knowledge that they could contribute to my research, were also receiving me as a guest in their house. As a guest, for the wife of a man who was being interviewed it would be rude to not be present, and therefore generally, there was often a spouse present. While not necessarily limited to or determined by ethnicity, this may have been part of the overall structure of the interaction, with my identity being partly revealed by language commonality, and partly by the nature of sampling (snowballing through contacts).

The addressing which occurs between my self and the participants also partly contributes to the construction of the event – typically I would address them as ‘uncle’ and ‘auntie’, as terms of respect and humility. Even without being related, or never having met before, these terms of respect are still manifest in many South Asian cultural frameworks and form part of everyday interaction. These terms of familiarity, respect and mutuality, do not afford a situation whereby the strictest definition of ‘interview’ is neither adhered to nor even consulted. The idea of ‘interview’, in a research setting, was not familiar to most participants, and in fact the interview was framed in the form of a ‘chat’, a normal everyday conversation which I was interested in having with them, for my research into type 2 diabetes. The decision to have a talk with them, rather than interview them, the former connoting a two way exchange and the latter a somewhat more linear and one way process, led to positive responses from all the participants.

Another aspect mediated by ethnicity is gender. As a South Asian man interviewing South Asian women often in their homes, quite apart from the generality of the assumed risk of allowing a stranger into the home, I was required to be ‘screened’, and a chaperone was fully needed. This would allay any fears about risks of physical problems, but also risks to reputation. The word ‘izzat’ is used in Gujarati, Hindi, Urdu and Punjabi to describe a number of themes, ranging from reputation, to honour. It is the maintaining of ‘izzat’, a morally positive and robust reputation as a woman in the community, that may be being performed when a chaperone is present – and the
performing and maintenance of this may be for my sake as a stranger in the house as well as the outside world. This was not evident in the interviews with older Gujarati women, but mainly in the interviews with younger females. The reason for this may have been the perceived risk of damage to a younger females’ reputation, where as with an older female there is already an established basis in the community, and the age difference between myself and an older female is great enough for me to class her as an ‘aunty’, therefore holding less moral risk.

3.6.2 Qualitative enquiry

In terms of the established philosophy of qualitative method, and the changing nature of this landscape then, it is important that this presence of ‘another’ in the interview is regarded as part of the overall process of generating data. As Cicourel stipulated (1964), if social action is often full of dynamics and contingencies, then why should sociological research not also be ready for such dynamics? This of course needs to remain within reason lest we opt for methodological anarchy; however the point being made here is that within the scope of the current research framework and questions, the presence of another person served many functions for the nature of the qualitative enquiry. Having a spouse or relative present placed the participant at ease; they were more comfortable, and able to relax into the ‘guided conversation’ (Pitchforth and Teijlingen 2005).

3.7 “Team Work” – The Co-Management of diabetes

The number of interviews in this study was a subject which at first glance seems simplistic, but in this case presents a dilemma – what constitutes an interview? Is an interview with a husband and wife couple, where one person has diabetes, but the other does not, still a one-to-one interview? Are the contributions of the ‘non-diabetic’ participant relevant to the subject and to be analysed? If the husband is asked a question and his wife also makes a contribution, should the interviewer stop this interaction, ignore the talk, and focus on the husband? The answer to all of these of
course lies in the way in which this research is situated. The research design of this study acknowledges that in the everyday reality of an illness such as diabetes, an ongoing chronic illness management process, success in managing it is usually contingent on the combined efforts of a team – be they friends, family or spouse. In the case of most of the people in this study, the ‘third’ person had been actively involved in collaborating with the diabetic from pre-diagnosis to current experience. They were involved in a variety of decisions and discussions about medication, combining remedies, managing the symptoms, as well as offering help and support in non-practical ways. The impact of the illness was also of course a multi-party process – the revelation of a diagnosis would have an effect on the spouse, children, and parents, in varying forms. For this reason a decision was made to fully engage in the process of data generation via the various sources within the interview. Sociology necessarily needs to take into account the varying and dynamic nature of social action within the research setting, in order to make a statement about this action based in empirical investigation.

Since the research questions focused on how diabetes was managed, how it was embedded within a socially situated position, and how ethnicity and culture impacted on this, it was clear that the diabetic’s life was impacted upon by their spouse. They lived together; operated in and outside the home together; medications or assistance with medications were often administered by spouses; help with remembering names, places, dates, physical help around the home, the maintaining of dietary regimes, and the adherence to religious or faith frameworks; all of these were often carried out in partnership with the spouse. It therefore seemed a natural progression that the interview, whilst still directed at listening to the main participant, could also allow for and be interested in the third person. In many cases this proved to be sociologically and qualitatively interesting material, and avoided the charge of invalidating a person’s identity within the research.

Contrary to Boeije’s (2004) suggestion that this ‘third’ person decreases validity, here it was seen as a resource for the study, which could be utilised for a rich account of
the socially and culturally embedded diabetes experience. This seemed an appropriate strategy since the management of type 2 diabetes was rarely a lone biographical project, but rather a personal and social activity carried out in the context of relationships (Peyrot et al 1987). People were aided by significant others in complex webs of knowledge, belief and products, so it seemed appropriate that a qualitative and situated sociology could engage in these relations rather than negate or ignore their value.

The discussion in this section echoes the work of other commentators in the field, such as De Andrade (2000), who argue that the insider position – such that it can be placed on comparable ground as the process of cultural validations in this study – is dynamic and constantly recreated throughout the fieldwork. The dynamic nature of negotiated identities in research is also echoed by Reinhartz (1997) who discusses the existence of multiple-selves in fieldwork. The changeable and fluid yet tangible nature of identity connection and formation in the field is an underlying theme in this study. It emerges time again within both field site visits and individual interviews as a social and cultural context for the embedded-ness of type 2 diabetes experience.

3.8 Cultural invalidations?

My role within the research setting, and the ways in which connections occurred – some through identity work, others through my own cultural and ethnic ‘insider status’ resulted in rapport and ease in the interactions. However this position has been critiqued for its possible tendency to inhibit conversations (Young 2004). In what he states is an ironic case, Young argues for the advantages an ‘outsider’ status can bring to social research, since it allows for a more critical view of the social phenomena being observed, and therefore will facilitate the kind of critical and intellectual endeavour which led to the fieldwork in the first place. In Young’s view, having a close connection to the research population can inhibit conversation, (therefore stunt the research), because of the comfort and rapport that has been created. Since being an insider the researcher is in a position of ‘knowing’ certain things – social and cultural
knowledge stocks – then these things are not worth spelling out or even talking about, because they are to be taken for granted. Indeed there were instances during two of the interviews when on probing for a response, the participant reacted in a similar fashion to Young’s respondents – mild bewilderment that I, someone who shared certain ideas, knowledge and ways of being (be they language or other) needed something spelled out. This was usually when I asked a question or probed for information about experiences. The participant’s bewilderment may well have stemmed from the view that having diabetes is not experienced, but rather managed – in a sense people simply got on with the task of living their lives. Thus asking a question about some aspect of it was at times met with limited responses. Within these interviews, as Young articulates, a sense of closure did occur where the participants simply felt no need to explain further. Again this demonstrates the dynamic nature of cultural validations and the relevance for the kind of reflexive fieldwork activity carried out here.

In terms of the role of the reflexive researcher Young argues it is essential that the goal of insider status – however that may be manifested in the research – is not sought at the expense of what the outsider status can bring to the research (2004). Within this study, the processes of cultural validation facilitated the fluctuating connections between researcher and researched, so that no unitary status (‘in’ or ‘out’) could be simplistically adhered to. A static and restrictive construction of the ‘knower’ status compared to ‘stranger’ status is not useful analytically. In addition the amount of time spent in the field sites and the interviews (one off interviews and one to two-day visits) meant that an encroaching sense of insider-ness was not experienced. Rather there were public displays of recognition, familiarity and endorsement, as well as private validations which took place in private homes and public spaces. All of these were subject to the usual fragility of social interactions (illustrated in mistaken identity, rejection of anything other than medical advice, and one case of unwillingness to engage).
Summary

The method employed within this study was qualitative in nature, being firmly based in the interpretative paradigms of empirical sociology, and used a grounded theory informed approach to generate and analyse data. The semi-structured interviews generated accounts and narratives which were situated and grounded in the cultural context and backdrop of the research. Aspects of my identity, history and cultural and ethnic makeup were connected via language, religion, country of origin and common cultural knowledge stocks, (in the ethnographic encounters as well as the interviews) to the participants, and this process of connection I have called ‘cultural validations’.

The validation process I describe here is an interactional process which explicitly demarcates the symbolic borders of sameness and difference that operate in human interaction. To observe cultural validations is not simply to ‘sail’ through access points and begin interviewing people without a problem. Rather it is analysing the vicissitudes of entering into the research relationship with all of what can be termed the ‘baggage’ of personal biography, and allowing this to mediate who one talks to, how this talk is engaged with, what role one’s own history, experience and knowledge can play, and what effect it has on both the research and the people involved. In a similar observation to other researchers exploring the experience-authenticity-positionality conundrum (e.g. Alexander 2004), being Gujarati Hindu and having some familiarity probably facilitated initial access but it was never going to be sufficient to carry the entire experience.

The following chapters (4, 5 and 6) demonstrate how this situated methodology generated a series of findings which related the diabetes experience with aspects of cultural and ethnic identity.
CHAPTER 4

‘DOING DIABETES’ - DIAGNOSIS, EXERCISE, DIET AND MONITORING

Introduction

This chapter focuses on the more practical aspects of the diabetes experience, such as the diagnosis, nutrition and dietary changes, exercise and physical activity, and the everyday monitoring of blood glucose levels. As with many of the findings in this study, there is a dualism and dialectical nature to the ways in which people experience this illness. For example while on the one hand there may be a straightforward ‘telling’ of the diagnosis process, there is on the other hand a ‘re-telling’ or re-framing of the diagnosis process, in which the respondent uses various resources to triangulate symptoms, using overseas information networks, and present this to the GP. This is far from a passive acceptance of established diagnostic systems, but rests comfortably within the lived social arena of the respondents’ experience. Similarly with nutritional ideas, people within this study would step from talking in general about what they could and should do, to being explicit about specific circumstances where blood glucose levels may be affected, and how they counter this. Health service literature is abound with research which, chronologically has proceeded from conceptually limited culture blaming theses (Gupta 1995; Hill 2005; Qureshi 1989) to more complex and contextual accounts (Lawton et al 2005). However, there remains a need for more substantial theoretical purchase – i.e. how are these notions of activity which are so closely connected to diabetes and health management, conceptualised, symbolised and acted upon? People admitted that the South Asian community as a whole were not physically active enough but they themselves were not part of this failing. Rather than write this as a ‘version’ or ‘construction’, here it can be framed as a performance of ‘private’ and ‘public’ accounts (Cornwell 1984). On the one hand people reported that there was some validity to views of people not taking enough exercise to help with the illness – but on the other, there were many other things which people were doing which constituted exercise. In addition, people had integrated activity into their
everyday lives, being very aware of the prevailing climate of exercise and nutrition apparent in everyday social and cultural media. Similarly, the monitoring of blood glucose was something which most of the respondents were acutely aware of and acted upon—having different indicators of high and low levels. Even those who had had great difficulty in the technical details and mechanics of the process were able to source local expertise to ensure monitoring. In addition, sometimes the medication regimes were not always simply taken for granted as “tablets for life”, as some accepted, but in some cases there was active adjustment taking place. Where a weekend of eating and socialising may have caused a peak in blood glucose, especially just before a doctors’ appointment, the participant rather than take the increased medication dose prescribed because of elevated levels, would simply continue on the old dosage to achieve stability. This demonstrates a need to maintain stability in the allopathic help seeking environment, but also a need to resist complete surrender to the regime, and retain control of one’s own body.

4.1 ‘Community’

Within this study I refer to the notion of a ‘South Asian community’ to describe and characterise the people within this study. However, this runs the theoretical and empirical risk of reifying what is essentially a fluid notion of collectivity and belonging. The word ‘community’, (while having legacies in Tonnies’ (Clarke 2001) conceptual binary oppositions between ‘gemeinschaft’ and ‘gesellchaft’) is used here to frame a sense of fluid sociality, where people move between groups, differentiated by utility and social and cultural need. In this way, there is really very little that appears like a homogenous South Asian community, as this thesis emphasises, but rather groups of people who given their biographical, historical and immediate experiences, can identify with resources that help to lubricate social and personal interaction. As Cornwell (1984) underlined, simply describing at-face-value accounts of cohesion and interaction within peoples’ lives is underestimating the divisions and disputes that may exist, and as raised by Bulmer (1987), leads to the idealisation of groups pictured as tight-knit and solid. ‘The South Asian community’ here is reflected
in a shared identification with what in this study was connected to being Hindu Gujarati, as this seems to be a main identifying factor (although not the only one). The word ‘community’ here is used to indicate belonging via language, country of origin, religion and sometimes caste. However, as is demonstrated in later sections, these are not rigid or fixed, they have a fluidity which far from being out of reach or control of social actions, are used dynamically and in the service of managing diabetes.

4.2 Finding out about the diagnosis

One of the initial lines of enquiry in the interviews was a question about how people found out they were diabetic. Given that over the last several years, the government and various organisations as well as academic and health research have all mentioned the ‘missing million’ – those people in the UK population who may have type 2 diabetes but are not aware of it – it was prudent to ask a question in this vein. The relevance of ethnicity of course is also a crucial element here as research has in the past indicated that certain sections of the population have differential likelihoods to access help, information and diagnosis (Nazroo 1997).

However beyond any issues related to ethnicity or culture, investigating how people found out they had a chronic illness such as diabetes is not only inherently sociologically interesting, but contributes to the overall intellectual puzzle before us; how do people conceptualise diabetes?; what do people do in their everyday lives to manage and deal with the illness, and in what ways are these mechanisms embedded in social context? Enquiring about how people found out about their diagnosis may then provide the beginnings not only of a story about diabetes management but also a road map, charting the territory of health and illness management.

Though finding out about the illness was usually a chance occurrence, the diagnosis was still contextualised by living with the symptoms for some time, so the process of acquiring the diagnosis and the actions and thoughts of people afterwards may illuminate the various mechanisms by which the illness was dealt with.
I asked a question about how they came to know they had this diabetes, and the answers were quite uniform. On the whole participants reported how they had the usually cited symptoms of tiredness, thirst, frequent need to urinate. Even though Dhansuk, who has been actively involved in the community, talks with ease about diabetes, as he has experience both in his family and through the Expert patient programme, his diagnosis was still a surprise:

...I used to go to the loo quite often, and I used to feel thirsty... I had an occasion to take my brother to the hospital, and I just mentioned to the nurse that I was having this sort of symptom so she said alright let me just check your urine. And she said did you know that you have got diabetes? So that's how I came to know about it.

Naresh, whose wife was also present at the interview again found out about his condition through a routine procedure for another ailment:

I found out about 5-6 years ago. I didn't know about the symptoms myself, but I went to have keyhole surgery on my shoulder, and had some tests, and that's when I found out about sugar levels. Otherwise I didn't have any other symptoms.

Although the interview below was with Rina, who had type 1 diabetes rather than type 2, her mother was also present in the interview and talks about the experience of watching her daughter suffer the symptoms, the strain on her life, ultimately leading to her making a doctor’s appointment for her daughter. Here she talks of the pressures and strains involved in interacting with her daughter, and witnessing her condition:

She would come from work, I would do all the work—cooking, everything, and I wanted to talk to someone at the end of the day, she would come, sit on there and go to asleep... I used to get so frightened about it, because what's my life
I've been home all day, done all the work, she doesn't have to do anything, she'd just come here and sleep, and I said no, we're going to book an appointment and you're going to see the doctor.

Given that the lead up-to a diagnosis involves not just the individual but an entire network of social actors, the above offers an interesting insight: it demonstrates that decisions are rarely taken in isolation and a plethora of important factors are accounted for - including the stressful and anxiety provoking affects on family members. Other participants' also had similar experiences, as well as some emotional and psychological effects such as short tempers:

I shout at people a lot. I lose my temper! Because of this diabetes, my temper is really short! If my wife says something to me, or my son or daughter say something, then I'm ok. I realise that I shouted for nothing. I get angry at the slightest things. (Pramod)

Diabetics get hot tempered. Wives, children, all need to understand this. But they argue with him, and his blood pressure goes up. (Kishore)

The onset of diabetes then, as has been documented had an impact both on the biological, social and the psychological realms of experience. Pramod, who is 60 and retired, living with his wife and daughter, is trying to explain his shortness of temper, which although may be for a number of reasons, in this context his account indicates the meaning he attaches to this event, and the significance it has for him. Kishore echoes these sentiments, and looks to the problematic interactions that can take place, calling on lay ideas of the causes of rising blood pressure. The impacts of diabetes however are often mitigated by factors such as being familiar with or having had some exposure to the condition, and is discussed next.

4.3 Familiarity
As Kelleher (1988) demonstrated, experience of diabetes is important in being able to cope with it as is the case with many chronic illnesses. As a result of such high incidence and prevalence on a global basis (WHO 1998), there is a sense in which this problem, while certainly not welcomed, may be partially expected. Many of the respondents were aware of the growing problem (it is often simply called a ‘sugar problem’), and much of this familiarity came through families and social connections.

Having someone in the immediate or extended family with diabetes functioned as an awareness increasing tool regarding the general nature of the illness, the medication regimes, the required changes in lifestyle, and the physical effects. Familiarity also functioned as a buffer to reduce the emotional impact of the diagnosis. For example, Kanti, an 88 year old widow, living on her own in Birmingham explained:

*I didn’t think anything because my mother had diabetes, at the age of 30, well I got it very late, and the doctor said its not an inherited thing, its because your pancreas is not working.*

“Apra ma bho che” is a phrase which was used repeatedly in the interviews, and translates to “there is a lot of it in our community”. The “it” being referred to is “sugar” or “sugar diabetes”; to have “sugar” or a “sugar problem” is to have diabetes. In this sense there was certainly a strong familiarity with the illness. When I initially explained the purpose and aims of the research, there was a general ‘knowing-ness’—indicating the interview was characterised by a knowledge and familiarity of diabetes with specific reference to membership of an ethnically distinct group.

When I asked participants about their first thoughts on knowing they had the condition, there were a variety of responses—some people did not report being overly anxious because of the experience and familiarity they already had, while for others the same sense of familiarity was the cause for anxiety:

*It wasn’t a matter of fear. I used to be a teacher- I know- I read the literature...* (Kanti)
Because my elder brother had it, and I saw his symptoms, as soon as I started having those symptoms within a month I went to see the doctor... when it came to my turn I thought that's not right, so I went to the doctor. (Kishore)

Naresh here talks about his familiarity with the symptoms and the potentially extreme effects of diabetes on the body:

At the time I thought this is a dangerous thing, it can make you blind, heart problems, can give you lots of problems. So you have to be very careful. I know one man who went blind.

The idea of being familiar with the illness is important here because it illustrates that within groups of people, loosely defined as faith communities, there is a level of expertise and knowledge about diabetes which might provide the basis for further work. This ‘expertise’ can of course be interpreted as ‘lay health’ beliefs which have their own logic and consistency (Gerhardt 1987). However they may also be thought of as ‘access points’, used by people to start the process of diabetes management. To have this familiarity often lessened the anxiety involved in the illness, but also served as a membership tool – hence the common phrase ‘there’s a lot of it in our community’. While the membership was not always welcomed – illness seldom is – respondents gained some source of comfort and support from there being a shared and collective illness space.

This seemed to serve a powerful purpose in terms of group membership and facilitated support and the active management of the illness. In a sense participants could be seen as social actors taking on board health discourse information about ‘South Asian diabetes’ trends, but rather than passively accepting these constructions, they could be seen to be utilising them to manage their condition. In other words, they were articulating in lay terms what they understood to be happening in their
community’, rather than fatalistically accepting this, they retained agency and control over their conditions.

Maclean (1991) discusses wisdom gained from experience and Kelleher (1988) discusses how this experience was sometimes more valuable in its specificity than a doctor’s general knowledge. Here however familiarity does not need to stop at the persons’ own experience of the illness and the body, but could certainly be extended to other people in the family or social circle with similar experiences. Additionally, this type of reflexive knowledge is not necessarily limited to adherence to diet, but could also be employed in the trans-cultural and trans-global transferral of knowledge and remedies, discussed in detail in Reed (2003).

4.4 The ‘Double Check’

Most of the diagnoses were as a result of chance – for example during a medical check up for another problem, blood results would reveal the diabetes. This however was not always straightforward, as some of the respondents used a ‘double check’ strategy – Naresh explains how this took place:

*The level was very high when I was first tested before the surgery, and I told the GP. He didn’t send me to a diabetic clinic or anything; but I wanted to know why this diabetes has happened. It was actually in India, in an article which talked about the tablets I had been taking, when I realised that the diabetes was a side effect. Then I went to my GP and asked him if taking this blood pressure medication might cause diabetes, and he said “maybe”, I said “no not maybe, it’s true.” And I showed him the article. Then he stopped my medication and put me on other tablets.*

While one would not expect this to be a straightforward process normally, as help seeking trajectories are invariably varied, it is interesting here how Naresh used a contact in India to send him an article which he then presented to his GP, suggesting
that the side effects of the particular tablets he had been taking may have led to diabetes. Only then was his medication changed. This demonstrates that though usage of health care and the taking on board of medical advice takes an expected form, there is also activated a strong sense in which responsibility, independence and proactive help seeking is present. This was not an isolated incident – others in the sample also operated this ‘double check’. For example Basanti is talking about her husband’s diabetes, but in this case it was an inverted check – the diagnosis took place in India during a holiday, and contrasted with a diagnosis by their GP in the UK:

*The doctors knew nothing about this. He’d had some heart operations, then we went to India, and he had some problems there, diarrhoea etc, and because he’d already had heart problems, we admitted him to hospital... and there on the spot, blood tests and everything, and they asked if he was diabetic, we said no. They told us he has high levels of sugar in his blood. He wrote a letter to bring back to the GP. We went to see our doctor here and told him. He said this can’t be. He got tested, and then it was confirmed.*

These processes described above point to one of the overall strands of this thesis – that embedded in people’s doing of social activity are active conceptualisations of what the illness is, what actions to take when a diagnosis is revealed, and how to activate a series of resources in order to optimise health status and illness management.

### 4.5 ‘Exercise’ and activity

As part of both the general health education / health promotion literature surrounding illnesses such as diabetes, and other conditions (obesity, cardio-vascular diseases, depression), as well as the specific literature on the health of black and minority ethnic communities, exercise has been noted as extremely important. Often this has been in the form of prescriptive notions of specific amounts of physical activity for
the general population, at other times this however has been targeted at specific
groups, such as the South Asian collectivity.

Participants seemed to be aware of a general health message regarding physical
activity and diabetes, and that they as a targeted ‘high risk’ group had a responsibility
to undertake this activity. There was also a sense in which they admitted culpability –
they did not exercise as much as they knew they should, and this contributed in some
way to diabetes onset. However, there is also present an on-going idea of ‘resistance’
– although people did reproduce generalised health messages about lack of exercise in
their talk, they also went on to elaborate how they did manage to get some exercise.
This seeming contradiction highlighted how on the one hand people were aware of the
constructions of South Asian high risk, and on the other hand were also self-aware of
the actual practices in their daily lives which contested this. These three excerpts are
examples of people talking about the reasons for lack of exercise in the generic South
Asian community, as well as reasons for being able to partake in activity:

_They tend to lead sedentary lives, sit in front of the telly, we Hoover, we used
to sit on the floor, we never had a washing machine for 20 years, people don't
walk anywhere, they get in a car. Most families have got 2 cars, I'm the same._
_Exercise and lifestyle, that's where it is._ (Rina)

_Taking plenty of exercise, whatever you can... rather than living a very
sedentary life, eating too much, just sleeping, not doing anything, being
lethargic, that's a sure sign that you are suffering._ (Dhansuk)

_I'm very careful with my food, no sugar in tea etc, but in rice and
carbohydrates you do get some sugar, so...I exercise as well, cycling, up-
downs (oot-bess), but walking is difficult because of the climate, and I've some
problems with balance, as recently I fell in the bath._ (Kanti)
It is also worth noting the construction of ‘us’ and ‘them’ categories, as in Rina’s excerpt, whereby ‘they’ refers to South Asians not having an active life, but this is somewhat countered by a mention of ‘we’. This is interesting because it demonstrates to some extent the way in which group membership is conceptualised within South Asian communities and the activities associated with people. This also relates to the previous discussion regarding the often quoted phrase “there’s a lot of it in ours” – spelling out that an individual perceives that this group is lacking in physical activity, but that the individual is also a part of this group. Referring to the group as ‘they’ may function as a distance creating mechanism, while retaining a ‘we’ in the later segment returns the individual back to the membership of the group. This line of analysis and interpretation has parallels with Sack’s membership categorisation devices (Sacks 1995). Although this type of analysis will not be developed further here, it indicates there are insights to be gained from constructions of ‘self’ and ‘other’ identity which are interrelated elements in this discussion of diabetes and ethnicity.

A number of participants also explained to me that they took part regularly in Yoga sessions, and while this was not extensive in the sample, it was the means by which they learnt about and engaged in the exercise which prompted attention. Interestingly Yoga has in the recent past been a dominant force in the health and well being arena, being offered in leisure centres and fitness gyms globally. These spaces are not primarily the space where elder Asians might frequent, but through the expansion of global telecommunication networks it is now a popular choice in the homes of South Asians in Britain: "...Asian yoga is huge in the UK - this guy has come over from India who's a yoga teacher and there's a whole phenomenon of Asian housewives up and down the country doing yoga in front of their TV at 7 o'clock every day" (Douglas 2006).

While the local temple in two of the sites (which also typically serves as a community centre) ran exercise classes for the over 50s an additional event is the televised satellite broadcast from India. In these cases, people were able to watch yoga sessions
broadcast from India, and listen to various forms of health advice from a religious and / or spiritual representative:

They show people just how many problems can disappear...I tried this yoga; it's made so much difference. There are even doctors there, who are being helped...I wake up at 5, do the exercises, (it) makes a difference. (Basanti)

The presence of medical doctors taking part in the sessions on the Yoga broadcasts provides a scientific legitimacy, thereby transforming what might be a 'private' practice into a perfectly acknowledgeable 'public' practice.

Basanti has weaved the Yoga sessions into her daily life, though it is closely connected to her adoption and adherence to herbal and traditional remedies for a variety of illnesses. The relevant point here is that through a trans-national conduit, using modern media there is a facility to maintain symbolic and physical interaction with cultural and ethnic identities. Overtly this may be through the physical and practical ease with which one can access television and watch or record a programme, so that one can practice the exercises. However symbolically there is also the underlying validation these activities are given by the religious and / or spiritual position of the expert or 'guru'. Further validation is given when as Basanti says above, 'even doctors are there', showing that even those who are practitioners of the biomedical paradigm can be engaged in terms of complementary and traditional health methods.

Again, this demonstrates that though participants show that exercise may be a contentious issue as far as diabetes and South Asian's are concerned, there exists resistance to the formal constructions, and they are played out in people's innovative activities. Activity and exercise as concepts are not to be seen as uni-dimensional units of analysis which are found in Western concepts of body health and fitness management. Rather as people have expressed in this research, activity is more an expression of social and cultural management.
4.6 Food, nutrition and diabetes

Diet and nutrition have also been the focus of much discussion and research in the South Asian health discourse. Many of the usual typological categories that are evoked are unhealthy and saturated fat diets, inappropriate cooking methods, lack of necessary vitamins and minerals (all of which have now been questioned) and this is invoked in the respondents' talk:

You know the problem is that in our cooking, there's so much frying going on, that all the vitamins are gone. Boiling is the best, but oil ruins it. (Naresh)

In our communities, there's too much oil in the food, whereas in English cooking its more boiled food, ours is oily. (Pramod)

They just don't look after themselves, they sit and have buttered cobs and samosas day in day out. We've usually eaten by 7pm, latest. People eat so late and go straight to bed; it's not good for them. (Rina)

The categorisation of groups in terms of 'us' and 'them' is also interesting here – because it belies a subtle reminder of the accountability involved in health practices. Naresh and Pramod are both men in their 60s and 70s, and include themselves in the groups that may not cook in the most healthy way. Rina however, who is of a younger generation (she is 40), a working professional and involved in work within the South Asian community uses the 'they' category. This may be a generalisation on her part but she is morally accounting for practices in the community, and placing her self outside of this group. Similarly here Basanti and Kanti ensure I know about their 'healthy' practices:

In my family's history we don't eat anything from outside. Since coming here in...my mum came here 1968, there were so many problems in getting our
food and yet my family has never eaten frozen or tinned food. Always fresh.
(Basanti)

I eat less now - I don't eat to a full stomach anymore, if I want 2 chapattis, I eat one and half; if I'm hungry for one and half then I'll eat one. But I'll eat my curries, because that's where I get my greens, for stamina. (Kanti)

While Basanti, a staunch advocate of natural and vegetarian food who cooks for immediate and extended family, as they live in a household with son, daughter-in-law and grandchildren, takes pride in not having eaten processed or pre-prepared food, Kanti tells me about how she is able to moderate her intake in a specialised way. There is differential calorific value applied to eating flour based items such as chapattis, and eating fibre laden green vegetables. Again, these extracts demonstrate that within these routine and mundane happenings, people have talked to me about the many ways in which they attach importance to managing the many aspects of the condition.

4.7 Social eating & moderation

The conceptualisation, preparation and consumption of food are of course cultural and social entities mediated by both tradition and modernity (Bradby 1997). This means of course that how people think of and consume food – especially when there are added elements of the effects on their body and the social impact on their interactions – will be facilitated by ideas of ‘social’ eating and notions of moderation. In essence, the people here did not simply make - or indeed not make – food decisions in a vacuum. Rather they took on board the requirements of their physical body, and located it within a social and cultural space, acknowledging that doing so would have impacts for their social and community relations.

One of the issues which emerged in the data as a result of probing was what people did regarding food intake when in a social situation. This presents a particular issue
for people with diabetes. Since type 2 diabetics are required to manage and control their insulin levels through a combination of medication and/or diet, this presents a particular challenge, and one which ostensibly invokes notions of stigma and the possibility of spoiled identity (Scambler and Hopkins 1986). However, (and this finding was also a form of validity check to ensure that the grounded theory generation and analysis was not being driven by expectations and pre-conceived ideas) people were quite pragmatic about what they did about these situations:

*I just tell them I won’t eat that, forget it. Because the temptation is always going to be there, but you have to think about yourself, and if I do eat this, then I’m the one who will suffer.* (Naresh)

*When it’s sweet stuff, especially if it’s the blessing at the temple, then I’ll have a bit, but a little. I won’t lie (to you), it’s not going to hurt you, but if you’re eating this all the time, then that’s different.* (Sunita)

*At Divali, if you’ve gone somewhere and someone hands you sweet offerings, I won’t have a whole bit I’ll have a little bit, and then no-one feels like I didn’t, I won’t feel I like I didn’t either. Why do I need to tell them? I’m not ashamed of it... I think for me I’m the only one in our extended family that is diabetic. I think when people find out they think well ‘oh, ok she hasn’t got much time’... or ‘oh dear, you’re...’ (Diabetic)’ and it’s like they feel sorry for you, and there’s nothing to feel sorry about, because that makes you actually feel worse. I don’t tell people because there’s no reason that people need to know really. If I need to tell people I tell people, if they don’t need to know then they don’t need to know.* (Rina)

In the statement above, Rina talks about a special occasion such as Divali (the Hindu festival of lights) and the need to maintain etiquette by eating a small offering rather than a large offering as a way to avoid offence. However, here she also talks about disclosure of the condition – by not having any sweet offering at all, she may be
forced to disclose that she has diabetes, and in her own words, ‘why do I need to tell them?’ The function of moderation mediated by social context can be dietary related, social etiquette related and/or stigma related, all interconnecting with diabetes.

This is by no means a ‘cultural’ account – by arguing this to be a specifically ‘South Asian’ facility would be committing the type of error this thesis intends to avoid. Rather than an ‘ethnically’ specific idea, it is more a demonstration by people that there are ways of moderating their calorific intake, but that these are always being played out against a social and cultural backdrop. Being Hindu Gujarati, attending weekly sessions at the community centre which is also a focus of religious events and social interaction, means that when an external social event occurs, there will need to be an amount of social diplomacy involved. This points to a facility and understanding of moderate eating.

Again the data demonstrate through people’s talk that their actions in both individual and social settings are expressive of non-passivity. Quite contrary to not only diabetes specific health discourse in academic research and government research, but also participant’s reports themselves of other South Asians, they tell me about how the risk is demonstrably resisted in everyday situations. They assess, monitor and evaluate the weight of the social significance of eating against the effect it will have on their diabetes. As we saw above at times the reason for partaking is to avoid offending the host; at other times it may have religious meaning, as in Sunita’s excerpt above. For her, a blessing from the temple is an absolute ‘must’, which has to be eaten, in however little portions one is limited to. Religion for her has played a central role in facilitating her management not just of diabetes but a range of adversities in life.

Kishore has called this moderation ‘balancing your books’, a metaphor he uses in the interview to explain to me how he conceptualises the management of the illness:

*Take today, I’m going to have a meal, and have a sweet offering, but I’ll make sure I won’t have anything else. I’m going to balance my books; I’ll use it*
wisely here. For us diabetics if you don't eat that sweet then you have the option to eat 5 or 6 different items. In the ladoo (sweet desert) it is solid and packed with sugar and you've spent your money. Whereas the other way, there's curry, salad, this, that, you can spend it wisely. (Kishore)

He goes onto to tell me that this 'balancing ones books' is how he explains diabetes management to other people that he meets in the community. It is an accounting metaphor, and one which he finds useful to implement and communicate, given his own training and background (accountancy). He finds this an easy method to relate the calorific intake management for diabetics on a day to day basis. For example, he enthuses about another of his metaphors:

You control your diabetes manually - it's not an automatic car, with one of those all you have to do is operate the break, when it's manual you have to make sure you change the gears all the time, diabetes is like that. The sugar control is manual.

What is evidenced above is again the expertise that people in this sample had. None of them were officially recognised, trained or certified as skilled or professional in any way connected to diabetes (except for Dhansuk who had fulfilled the requirements of the government's Expert patient programme). This expert-ness was derived from connecting with life experiences and biographical backgrounds in order to both manage the condition, but also communicate advice to other people.

The relevance of this connects with the overall way in which respondents were able to talk about the possible causes of diabetes such as sedentary lifestyles, poor nutrition, and lifestyles, but also then talk about the ways in which they were active in their personal and social lives combating these 'risks'. These strategies were not individualised decisions, rather they were part of wider social relations - when people made a decision to go for a walk, there was inevitably a role to be played by a friend or neighbour:
Well I go walking around here; one round is 40 minutes. Now I walk a little more slowly, maybe it takes 50 minutes, 1 hour. Before I used to have company, my friend used to walk with me, but since he died, it’s gotten less; then I had an operation done. Now I’m starting again. (Harish)

Another respondent told me that before his diabetes onset he did not get out much for exercise, but since he knew about the diagnosis he had arranged to go for a walk everyday with a friend of his, a routine he had set up.

4.8 Food away from home

The management of dietary requirements is also something which becomes very much a part of the diabetic’s life routine. As demonstrated above, exercise and nutrition are rarely isolated entities, and similarly, ensuring adequate intake of calories also becomes part of the life landscape for many respondents. Bharti tells me how going on any trips in the car could be a risk, so contingencies are planned, as explained here:

When my sugar is low, I get dizzy, like I’m going to fall, body goes loose, the nurse told me that when that happens I should eat something like a biscuit, water. So whenever we go anywhere, we always take these things with us. Like if we go to a wedding, the timing of the food is different...Well, if it’s at someone’s house, I ask them for a biscuit or something. Or glucose tablets - just take 3 at once and straight away your sugar is back, so if you go somewhere it’s handy.

Similarly, Kanti who is 88 years old, explains how in order to save money and maintain her dietary intake, but also as a symbol of her independence, when she is called away from home and asked to carry out a favour for the community, she insists on taking her own food:
I take my food from home. Breakfast, lunch, dinner, tea, coffee I take myself. I look after myself. Tomorrow if something happens to me, well God only knows, but today I'm looking after myself.

These should not necessarily be construed as 'ethnic' frameworks, but rather strategies and mechanisms for dealing with the daily vicissitudes of diabetes as a lived phenomenon. They are cultural in that within the immediate physical and imagined locality people could call upon shared ideas, systems of belief and information, which connected with a wider entity, sometimes internationally.

4.9 The body in diabetes

The progression from having some familiarity with the illness to having a diagnosis, through to living with the condition is also influenced by the respondent learning about their body over the course of the condition. Many of the respondents employed a particular strategy in tackling the illness, which was related to their curiosity:

*It's in my nature. If I get a headache, I go into the books to see why the headache is there, how should it be dealt with, what food should I take, avoid, I have a passion / interest / curiosity for it. Being a teacher, I was a science teacher, so naturally I had this curiosity to find out about these things. (Kanti)*

*Yes, there was a time when I was studying this subject. I like to analyse things. Why do things happen, why might I get a headache, and find a solution. I say if you want to eat something you should do, but you must balance your books. (Kishore)*

*What should I do, shouldn't do - with me, I just wanted to know what's the solution to this? It's my personal experience to want to know myself that taking something has a reaction. (Naresh)*
Sunita talked in detail about her difficulties with the illness, and a variety of other medical problems she had, for which she was taking medication prescribed by the doctor. She explained how she found it difficult to understand the glucose monitoring using the machine she had:

I have a machine, I bought it, but I just don't know how to use it...I take it, take the blades out, just don't know what to do with it...I mean its not that difficult.

Because of this uncertainty about how to test her own blood sugar levels, Sunita regularly goes to her local pharmacy, where she can speak to an Indian gentleman there, and get her blood tested for a small fee:

I often go the chemist, pay a pound, and they do it for me...the doctor's surgery doesn't do it anymore...they don't check sugar, pressure...they say you have to go to town for all that. It's all changed now. Before there used to be a nurse there, but now...the doctor is too big to do things like this...

Sunita is demonstrating that while she lives in the shadow of uncertainty about the technical details of the illness, she can manage her medication, and though she cannot use her glucose monitoring machine, she is able to locate a resource to help her. In her case she finds a Gujarati speaking pharmacist to check her levels for her, either as a routine occurrence or when she feels the need — this need is determined by her monitoring her body.

This was also demonstrated in Harish's expression of the ageing body - again much the subject of sociological work in the recent past, but more rare when connecting to ethnicity and health. Harish explains to me how there is a slowing down process with ageing, but that this also has connections with his interactions with other people:
Resistance becomes lower, probably due to old age, (you) reflect back on the people you are dealing with, and they underestimate and try to dominate you...try to injure you more, and it becomes more frequent than when you are young. And as you become older you get all sorts of ailment, there's no cure for it. See nowadays, with medicine and this and that, its more comfortable, it prolongs life, but certainly you can't avoid it. Weakness is normal, one by one the limbs, you can't go up the hill, its all down the hill, and you have to accept that you're going down the hill now, you can't go up the hill.

Here, I asked Deena about her worries when she first found out she has diabetes:

Yes of course, worries. Thoughts like where did this come from? Before when I first arrived from India, nothing would effect me, even the cold. I used to go around everywhere. Now as I get older I can't even take the cold. Even when I wear so many layers, sweaters, jumpers, even then.

This sense of knowledge and awareness of the body via both everyday existence and the presence of the illness was present in most of the interviews. The presence and knowledge of symptoms, related to diabetes or not, was a common report in the interviews, expressed in a number of ways but having a common thread. As we saw earlier with diabetes symptomatology, people talked of many complaints, some of these leading to a visit to the GP for a check. In other cases there would be a sustained period of time with the symptoms before diabetes was diagnosed. In either case, the individual had been living with the illness, and all the well documented facets of this were in evidence (see Kelleher 1988; Anderson and Bury 1988). The emerging narrative theme however was that there was a sense of expertise in one's body which regardless of technical or biomedical know-how, allowed the individuals to assess their bodily state, and make appropriate adaptations to their behaviour and / or physical environment. Given that so much of the extant literature in diabetes discusses management and control, here there are corroborating parallels in the data, and yet as far as the South Asian diabetes literature extends, there is relatively little which
focuses on this as a conduit to an illuminating theoretical statement. Research may describe activities, but not necessarily analyse and interpret them in light of identities and social relationships. Here, control of the individual body, the immediate environment, the medications to be ingested, the nutritional requirements, and the knowledge and awareness of effects on the body – positive and negative, were mediated by active and dynamic notions of cultural identity.

Summary

The elements discussed here are part of the overall thesis – that people are actively negotiating both their personal and social contexts in the arena of diabetes experiences. The superficially straightforward idea of being diagnosed is now transformed into a process which often is revealed by a chance occurrence and is mediated by and through culturally located ideas, but also connections that are wider than the individual’s immediate space. Connections in India and other countries allowed for a buffer zone of acceptance and as Naresh and Basanti explained above, the diagnosis would not simply be accepted, and the ‘double check’ or a differential system would be utilised. Not all the respondents had the capacity or opportunity to do this of course, as this required confidence and connections overseas, even if these connections would just send a newspaper article or were available over the telephone. However, far from being isolated or deviant cases, they represent different forms of a common thread. Even those respondents who did not have overseas connections were able to employ pro-active systems in the diagnosis process, negotiating diet and nutrition, and taking part in exercise. Many of these systems were related to religious beliefs, but some were also active social networks and the biographical accumulation of experiences of adversity which will be discussed in later chapters.

Pro-activity, mediated by familiarity, social networks and in some cases religious frameworks reinforced the individual’s ability to cope with the condition as it was embedded within social contexts. Even though there was talk of culpability and blame – sometimes allocated to ‘people in our community’, sometimes to themselves, it was
the private, personal body, as embedded within social and cultural contexts that was the site of activity. These demonstrations and expressions of active negotiation can be underlined by the on-going theme of 'resistance'. This is the analytical idea of people demonstrably resisting constructions of passivity and high diabetic risk that have been prevalent in research in a variety of health research arenas through their talk and social action.

This chapter identified several themes emerging from the findings which help to explore the research questions originally set out. The initial diagnosis process, their symptoms and what people thought about this and how they acted upon this was important in getting to know about people’s responses, their anxieties, and the ways in which obstacles – psychological and emotional as well as physical and structural – were dealt with, and many times overcome. These were talked about in ways which although show uncertainties, disruptions and changes in people’s lives, also show demonstrable notions of continuity. Using the mechanisms of culture and ethnicity known to them via their biographies, histories and experiences, they showed forms of ‘resistance’ to what we might call constructions of a particular South Asian diabetic identity. Through this resistance people here were creating and maintaining personal and social order, negotiating relationships with family and other networks and weighing-up the impacts on social connections. They used knowledge of their own bodies and the relation to external structures to negotiate how diabetes was positioned in their lives.

Within this account type 2 diabetes has been characterised as a processual continuum, both in terms of the specific diabetes related changes one experiences, but also in terms of the related aspects it may be located in, such as the social and cultural context in which it appears. To acknowledge this continuum of illness management the emergent themes also reflect that rather than discrete ‘blocks’ of experience, there is a linkage between major elements of experience. The findings are one part of the continuum, and are extended in the following chapter (5) to another major theme.
related to the kinds of remedies, medical systems and knowledge people rely on in getting help for their diabetes.
CHAPTER 5

USING COMPLEMENTARY SYSTEMS AND REMEDIES

Introduction

Within this study participants engaged with my role as interviewer, but also demonstrated a perceived link or connection to an identity I might have held. This facilitated the discussion and generated information about a range of areas related to diabetes management. As elucidated in the previous chapter participants had a range of strategies and trajectories which they employed in help seeking for the illness. They utilised the allopathic model by seeing their GP, either as a first port of call or as a result of a routine check which revealed high glucose levels. However these processes were complemented by a range of entities such as individual and collective knowledge, the role of familiarity with diabetes either in a practical sense (an immediate relation with the illness) or as a notion (knowing that many people in the ‘community’ had diabetes) and a complementary system of remedies and medicines.

One of the major thrusts of the thesis was to find out what people did in their management of type 2 diabetes. Obviously this is a large and general enquiry that needs breaking into constituent parts. However there is a logic in the need to stay with this general notion, because it envelopes actions and ideas as manifested in people’s daily lives. The ‘doing’ of social action, what people actually act out is where some insights might be gained, and in this section participants explain how their knowledge and experience of traditional and herbal remedies play a part in their diabetes management. This chapter deals with specific elements of traditional and herbal remedies and the syncretisation with allopathy.
5.1 Using traditional and herbal remedies

The use of traditional medicines for a variety of illnesses is not a new phenomenon in the South Asian community or on a global basis. Herbal medicines have been quoted in use since 6000 BC (in the ancient Hindu texts Rigveda and Ayurveda), with 600 plant species being used in various formulations (Subbulakshmi and Naik 2001). An estimated 80% of people living in (so-called) ‘less developed’ countries rely exclusively on traditional medicine (Farnsworth 1994). The use of complementary and alternative medicine has been widely treated in both research and practice (Cant and Sharma 1994).

Established discussions of complementary and alternative medicine (CAM) systems focus on changes in the relationship between practitioner groups and the state (Cant and Sharma 2002) so that what is being underlined is professional and political comparisons between official groups. The use of herbal remedies – while certainly having overlaps with officially recognised and established CAM systems such as Ayurveda – do not reflect an official, expert system. Rather there is a difference between an official and ‘expert system’ of medical training and what can be classed here as the anthropologically informed ethnomedicine, or the ‘folk’ component of Kleinman’s (1988) popular, professional and folk triad, which sits comfortably as an alternative element within the range of extant healing pluralities. The terminology is also important as Saks (1992) argues, a term such as ‘complementary medicine’ can conflict with the fundamental bases between types of medicine. He suggests the term ‘alternative’ because it more readily takes into account the division between those ideas supported by the medical establishment, and those which are not. Again, these are debates of profession and politics, and by and large do not represent what people were actually doing or practising in their private lives. However it does open up the issue of where ‘folk’ or ‘lay’ medicine, especially those which are situated in ‘local knowledges’ and biographical, experiential histories, can be placed comfortably.
While the disadvantages of using some herbal remedies have been documented (Wood et al. 2004), the participants in this study were quite aware of the advantages and disadvantages of their usage—albeit not biomedical or biochemical awareness. The important feature is that these herbs were used with medical systems, and even then it seems only when there was a background knowledge of the product. Once any adverse side effects were felt, the usage was stopped, and in some cases there was a strong scientific case made by the participant for the need for control in these usages, because of the unknown nature of the active compound.

Within diabetes, there are a number of studies that report how people within South Asian groups use many herbal remedies, usually if not always as a complementary method rather than alternative. It came as little surprise that participants in this study had knowledge of these remedies, and in many cases used them extensively. However, what is interesting and relevant is how these remedies are used, the ways in which both the physical and intellectual products are acquired, and how we can interpret both their usage and what people say about them.

5.1.1 What people used

Participants talked about a range of non-allopathic remedies, some of which were commonly used as herbs and spices in cooking such as Methi (fenugreek), harrddar (turmeric) and ajmo (ajwain), while others were vegetables such as karela (bitter gourd) which were widely known and used as a remedy for diabetes. Other less well known items were also mentioned such as a ‘root’ substance, and a general ‘bitter’ powder which people ingest to help control glucose levels in the body.

There was also a variety of ways in which these items were taken, from powdered forms taken with water, cooked as a curry or snacks, as a liquid form, and even crushed skins of the vegetable karela turned into ice cubes.
Some participants required prompting and specific questioning about their use of ‘any other’ remedies or medicines, while others, such as Deena decided to talk about these complementary remedies very soon into the interview and talked openly:

*I always check my levels, and then take my tablets, and if I need to I’ll have some chocolate or something. I’ll also take some “kurvat ni phaki”...this makes quite a difference to me. This is from Dubai – I take just a little sometimes in the night when I wake up...whatever happens I always take my medication, but then if things get bad, I take a carefully measured amount and take that as well...I use karela as well, I use this quite often...I make a curry out of this and Methi, and I make steamed Methi – I’ve made some today.*

When I ask Deena about her glucose levels she tells me about how she checks it, and the herb she takes, including where it is from:

*Yes I do, I check sugar, 2-3 times in a week. If I feel my head has become heavy, then I check. Sometimes if it’s too low or too high at night I check. If it’s too low, then I’ll have a chocolate or something. If it’s too high, then I’ll take a tablet or have some bitters... it really makes a difference.*

She goes on to tell me when she takes it and importantly that it is used as a complement to the prescribed tablets, not an alternative:

*Often when I wake up, then I take it first thing, 3, 4, 5 am, then I take a little with water, 2 glasses of water. I always take tablets as prescribed, but after that I’ll take this if I need to.*

Rajesh tells me that this combining of remedies, this ‘syncrecy’ is effective for him:

*I do take herbal. Somebody sent them from India, one tablet per day. I’ve been taking this remedy since the last 6-8 months...I mean my results were around*
7.1, since I started that remedy - plus my normal medication, its been reduced to 6.9. I take the tablets and the herbal.

In the above excerpt we are being informed that 'efficacy' is reached through the use of a herbal tablet – sourced from India which is common in this sample – and the assessment of this efficacy is in purely medical terms – the participant’s Hb levels (HbA1c is a test that measures the amount of glycosylated hemoglobin in blood. The test gives a good estimate of how well diabetes is being managed over time). He is comfortable in expressing his blood sugar level in scientific / medical terms as used in much professional diabetes literature and education, but is equally comfortable in allocating the cause of this to two methods – the biomedical and the herbal. This ‘syncretic’ approach is a common practice for the people in this sample and symbolises the variety of connections participants had to different systems of knowledge. Additionally and importantly it symbolises the doing of social action – in this case manifested as a form of resistance to constructions of passive health and / or a risk laden South Asian diabetic identity.

Again, and as will be discussed below, there is both an international connection in terms of sourcing the product and a local one, as many of the items mentioned here are widely available in South Asian grocery shops throughout the UK.

Oh yes its very good. I eat Methi in the morning, it's the best stuff. I make a powder out of it, in the morning I have it with some water... there's iron in it to help with strength and coping with pains. I've got to this age and yet I've never had hip problems. Then there's this Jambu powder, that's really the best for diabetes, which they sent us from India. (Naresh)

The variety of products people used were sourced locally and internationally, and were used in combination with other products, including allopathic medicine. The emphasis in many of these interviews was that there was a strict adherence to the prescribed medication for diabetes, but also a parallel adherence to traditional / herbal
remedies, which were part of a person's cultural history, and maintained through local and international connections, perhaps indicating the dialectic of the global and local which Giddens (1991) discusses.

5.1.2 Reasons for use

There were many ideas participants had about why they might use herbal and/or traditional remedies. Some of the participants had heard about a diabetes-related herb or vegetable from a friend or family member, and others talked about the family tradition of using these methods. Others explained to me their reasoning for the choice:

Well at the moment I'm eating "Methi" (fenugreek) - you put it in water overnight and just drink the water...I'm just trying...because I do believe in Ayurvedic medicine. But I'm also very pro-western medicine as well - Tablets and things like that, because I think they have put in a lot of research into it and a lot of effort and a lot of money, and come out with these sorts of tablets so they must be good... it's a question of trial and error. (Dhansuk)

Again as we saw in Rajesh's excerpt, using or in this case trying traditional medicines is perfectly combined with allopathic medicines and again, there is a dual recognition of scientific and traditional efficacy, similar to Basanti's statement regarding the presence of medical doctors appearing in Yoga broadcasts from India providing scientific legitimacy.

Kanti tells me what she takes as a remedy, but more importantly why she takes it:

Firstly I take a quarter spoon turmeric, with warm water, then in another glass a quarter spoon methi, and in a third glass quarter spoon ajmo. So in the stomach the gas is lessened. As we get older the digestion power is weakened, so food isn't digested as easily.
In the excerpt above Kanti talks at length about herbs which are commonly found in most South Asian households as well as most grocery shops which stock South Asian cooking ingredients. These items are taken systematically as a routine, quite like a prescribed medication – but the reasoning behind their use is explained. There is an acknowledgement that the ageing process brings about weakness and gradual degradation of the body – which can be countered by using these herbs:

*Look, turmeric is an antibiotic. So I don’t need to take antibiotics. Otherwise a lot of the time for diabetics they have to take this and that, but with me where I have been hurt, it won’t go infected, otherwise usually if you get hurt, you have to take an anti-biotic. I burnt myself about 5-6 months ago, I had my coat on and it stuck to my arm, now it would usually become infected, but with me no, so the antibiotic is there, and Ajmo lessens gas and helps digestion.*

The use of these herbs however is not just illness specific – sometimes it is a generalised belief in their efficacy, as told here by Basanti, who uses them extensively along side allopathic prescriptions:

*Methi, linseed, my son takes a bottle with him, my grandchildren, all take it. Just at the weekend I gave them all doses. At the moment they’ve all got colds, so I put together a remedy - a mixture, liquorice, turmeric, some others. It helps. When my grandchild was born, they said he had asthma - we used only these herbal remedies, and he’s never needed the pump.*

The generalised use of these remedies passes inter-generationally, and has both a routine and focused use. The implication for diabetes is that both Bikhu and Basanti use allopathic and traditional remedies, are able to manage their illness, but also extend this use to their immediate family. The cultural tradition of herbal, traditional or Ayurvedic systems is maintained inter-generationally, from a focused and illness specific personal use, to a general health preventative use for grandchildren. Again, this demonstrates that participants like Bikhu and Basanti did not have a polarised
acting out of medicine use, as they used several forms in combination, even though they were clear about their polarised opinion / view of which system was better in the long run:

*The chemicals that go into medicine - in our 'desi' (Indian) medicine there's nothing like that. Ok, the effects may take longer, its more long term, but it does make a difference.*

The possibility of the side effects of allopathic medicines is also discussed by some participants who were reassured by the natural-ness of herbal remedies. When I asked about the combined use of diabetes medication and herbal remedies, Naresh replied:

*It's fine, there's no side effects to it, its all herbal.*

Kanti was also acutely aware of the effects which biomedicine seemed to have on her, describing it as a ‘Mahabharat’ (a religious narrative located in the history and mythology of Hinduism) in her body:

*Recently I found the medicine has had reverse effects on my body - so I went to the doctor and I said I don't want any medicine apart from diabetes medicine. Herbal medicines haven't got reverse effects, these have. You know we say about Mahabharat, I said if it (biomedicine) goes into my body there will be Mahabharat in my body. So I don't want any war now. When I did not understand I took it, but now I understand that it has given me reverse effects I stopped it.*

These demonstrations of the 'naturalness' of the herbs and vegetables people are using have also been observed by Sharma (1995), underlining the concern about the possible side-effects of biomedicine. What is not being questioned in this thesis is the relative safety of either of these forms of remedy, but the ways in which people *reason* their usage - the articulations of efficacy and safety which are rooted in
explanatory frameworks of both culture and ethnicity. There is a sense in many of these narratives of traditional, herbal remedies being firmly located both within a cultural and ethnic positioning, but also within Hinduism itself, so that the knowledge of these remedies, as well as the ability to utilise it comes from a Gujarati identity and a Hindu identity. This is interesting because it helps to demonstrate how syncretic usage of systems is not usefully characterised as an ‘either-or’ binary unit, but rather a dialectical relationship. If we observe how these usages are demonstrated in diabetes management in the UK by first/second generation Gujaratis, then we can start to see a sociological entity in the fluidity of cultural and ethnic identity forms within the relationship to health and illness.

Although participants above talk about the safety of the use of these remedies, they also talk about the overuse of them and the effects on the body:

*What I did was I crushed karela skins, and made them into cubes, so everyday I would pop one cube in hot water and drink it. I did this for about 1 and half, 2 months. Then my eyes were watering heavily. So I met one ma-ji (an elder woman), and I asked her why do you think this is happening? She said your not drinking karela juice are you? Stop the karela juice, I did and within a few days my eyes stopped watering. So certain things are suited to ones body, and certain things are not. You have to be your own doctor and treat your body in a way which pleases you. (Kanti)*

Here Naresh warns of the overuse of a herbal malaria remedy:

*The other thing is Neem powder – it’s good for malaria. We used to use it in India. It’s very strong. If you take too much, it brings too much cold to the body. We brought this bottle from here. Methi - you can only take so much of it, because of the iron in it - too much is not good... We alternate these remedies, to balance the different things.*
There are parallels here between the use of participants’ knowledge of Ayurvedic humours and western humoral formulations - the body’s need to be in a balanced state consisting of ‘hot’ and ‘cold’ elements (Helman 1994). For example, as Helman tells us, English lay health beliefs about ‘feeding a cold and starving a fever’ stem from these ideas of counteraction (1994:14). Humoral theory rests on the idea that all substances have a hot or cold element to them – a “symbolic power” (Helman 1994: 13) and for optimum health the body must be in a balance between these two states. In Ayurvedic medicine there is a complex interplay of the constituents and inter-constituents of basic elements of the universe and the body - health and illness rest on the interaction between them. These parallels support Jobanputra’s (2005) findings that there was no significant health belief difference between British Gujarati Indian immigrants and British White people. However, the interest and focus here is not on comparison between groups – this runs the risk of setting up a conceptual system of ‘other-ness’. In examining what people explain in their stories there is a useful way to illuminate how decisions are made, regarding the wide and varied remedies available to someone and the interaction between their health and location in society.

In addition to the inherent properties of the herbs and vegetables themselves having a potency to be regarded and ingested with caution, Kishore also talked about how in contrast to many of the above excerpts, it was dangerous to combine herbal and biomedical systems without consulting a doctor. He explained by telling me how the medication prescribed by the doctor is a pure and tested form of karela, and that it is ingested in exact amounts by taking tablets. The dangers for him of using karela are clear:

... The problem is that typically people will eat karela. But this is an impure form of insulin. So when you eat a karela, you don’t know if you’ve eaten 5 grams or 10... the actual stuff the GP prescribes - it’s a pure form of karela. The doctor has analysed and knows that in a day you use these many calories, you need this much insulin. The doctor has assessed you. But if you eat karela, you eat one, but how do you know? 1 or 2? If you’re eating 1, what if there’s
not enough substance in there? In the olden days it was ok to eat karela because there was no modern research. Secondly in India, Africa, if you need to see the doctor you have to pay for it, so if you can deal with it at home, then it was better. The doctor prescribes 10 grams of metformin. You go home and eat 4 karelas, your doctor doesn’t know, your sugar levels end up negative, the next time you go to the doctor, he sees this, and prescribes you 5 grams, instead of 10. After a few days the karela taste too bitter so you stop, so what happens? You’re playing around. I advise whatever people are using talk to the doctor. I will not take any alternative medicine without consulting my doctor.

Avoiding focusing on the scientific validity of claiming that karela is an impure form of insulin allows us to avoid truth judgements and focus on the activity within the talk of the participant, and what is revealed about his conceptual expressions. This cautionary note is more about a general and wide use of remedies in combination with biomedicine rather than a specific substance, and appears almost as a call for a self regulation of combination uses, as echoed here:

Ayurvedic? No, I don’t use it unless I know what it contains, and before I take anything I should be sure of the chemical contents, how it will react with the body, react with other medicine I take... Unless I’m sure. (Harish)

Using this ‘lay-scientific’ approach has both perceived advantages and risks. While some people used the scientific validity of allopathy in conjunction with traditional remedies to explain and / or justify their decisions, others like Harish used this scientific viewpoint to avoid traditional and herbal remedies altogether.

5.1.3 Reasons for non-use

The use of these herbal and traditional remedies as we see above is not universal. However, the reasons for non-use also provide us with an insight into how these ideas
are conceptualised and used in everyday life. Harish for example in the excerpt above does not use any kinds of herbal remedies because he is unsure about the side effects. This is in stark contrast to Bikhu and Basanti above who are wary of the side effects of biomedicine. Rina found the ingestion of these remedies unpalatable:

Someone once did give me some 'phaki' (generic herbal powder) kind of thing and I knew I couldn't do that; it smelt disgusting. So I thought I'd have it in water. I did, but I was making myself ill with it, feeling sick, so that hasn't really worked. Someone said karela, but I've never-I don't think I could.

Even those people who used the herbal remedies extensively did so knowing about the problems of their usage, and maintained all the prescribed medications they had. While speaking of the inherent natural 'safety' of these items, they also knew about moderate usage, and the pitfalls of not taking this seriously.

These conceptualisations of what is safe/unsafe use are not simplistic arrangements of passive acceptance of knowledge, nor are they forms of non-compliance or discordance. Rather they are active negotiations of ideas, framed within personal experience as well as immediate community networks, which are also extended to international borders.

5.1.4 ‘Expertness’ / Life experiences

The participants in the research were keen to talk about their histories sometimes requiring probing and prompting. In accordance with the thematic line of this study, people again demonstrated a variety of ways in which health and illness are related to the social context of daily life, in ways connected to history, biography and experience. These connections are also part of the fabric of this thesis through the methodology employed and the theoretical underpinnings therein – the processes of ‘cultural validations’. Using these ‘life experiential’ frameworks participants revealed
fragments of their histories and experiences to me, and talked of how they effected them in the present day.

Many of the participants talked of specific experience, such as Kanti, who revealed she was trained in medicine, before she was forced through family circumstances to abandon her studies:

*In India, my (school) principal was a European, and the science teaching was very good. It was one of the best state schools, the medium of instruction was English so we don’t have problems with this. From that I decided to study medicine, first I got a sponsorship to study medicine, then I did 2 years and my father fell very ill, I was the only daughter. His wish was to see me married, and I thought well what’s the point of me being a doctor and my father dying? It wouldn’t bring me happiness, so I sacrificed myself. I became a teacher instead, as you can’t do much with half a degree.*

She also goes on to explain:

*As a teacher I expanded my knowledge, in Nairobi, I was known as a “doctor without certificate”. People from all over used to phone me and ask me “... this has happened, what do I do, what medicine do I use?” I know desi medicine and other medicine.*

This complementary and syncretic use of medical systems permeates many of the interviews in this study, and characterises in a useful way what Eade (1997) pinpointed as cultural construction, and which Reed (2003) has also discussed in some detail. In this study it also serves to demonstrate that a participant’s notion of their position in the UK is not limited by time and place. Rather it is fluid across histories, places and the lifecourse. This fluidity is manifested in being familiar with different types of treatment and health conceptualisation.
Similarly, Deena, a widow talked of how she knows about the remedies:

Well, we’re from India, and my mother and others used to use them. My brother was really very big on these remedies. Very often he would write to me and tell me about them. Gas in the stomach for example, my brother would make up all these tablets and send them to me. So I used them here as well. We know all this because we were in India. I came here after 40 years in India, I was a teacher there in school.

In using Methi in her curries, Deena is employing a cultural framework which takes local knowledge as its base. These ‘knowledges’ as Ferreira et al (2006) have elucidated in recent medical anthropological studies are part of the biographical and historical makeup of a group of people. How this knowledge is acquired, learned and utilised symbolises very much the antithesis of ‘passivity’ and ‘culturalist’ explanations which have been put forward in the past in relation to this area. Using these herbs and vegetables and maintaining the practices which were learned as part of growing up can be regarded as a way of locating and maintaining one’s sense of self and identity. Given that food and the rituals surrounding its preparations and sourcing, especially in light of ethno-medicine and ‘folk remedies’ has an important position in cultural and social contexts (Helman 1986), this can be seen as a biographical connection to place and time situated in healing and health practices.

This sense in which participants were gradually telling a story not just about the ostensible ‘diabetes research’ nature of the work, but more accurately, about their life positions was present in most of the interview situations. This however is not to be located statically as a reified outcome of the research, but rather is inherently and intimately woven into the fabric of the relationship between the methodology employed here and the overall study. As Nettleton states “when people have the opportunity to give voice to their experience of illness, it becomes evident that their accounts are woven into their biographies (2006: 81). Within this study and with reference to this section of findings we can see how participants are compelled to
involve their history and migration experiences in their explanations of how they have come to know the things they know. When participants talk about how they know about herbal remedies for diabetes, they are maintaining a cultural connection in temporal, spatial and symbolic orders. In other words, by using the ‘illness narrative’ (Kleinman 1988) as a mechanism for communicating biography which is necessarily over a period of time and space, participants are able to get across a notion of their identity.

For example, when asked for a fuller explanation of his reasoning regarding his refusal to use any traditional or herbal remedies, Harish becomes reticent, and laughs. When I probed further (only after gauging the appropriateness of such an action; a rapport had already been established) he explained how this was his ‘background’. Here, proceeding from an earlier part of the interview, Harish tells me about his ‘background’, and how this relates to his decision not to take traditional remedies:

> You talked about Ayurvedic medicine, but I don’t believe in it. You get yoga here as well - they tell us do a bit of yoga, and your diabetes will go away (laughs), I say no thanks, I don't want that. I told you about my background before...in India I have experience of these people, at close quarters.

> My background (laughs). Because my background is such that I have a vast circle of various people, work, experience, professional...I'm talking about my background. I'm an educated person, and in India, my education...in India I had a vast circle of all sorts of all sorts of people, with all sorts of backgrounds, so I can talk to any sort of people and try to gain from their experience.

Harish here is showing me that his non-use of certain forms of remedy is based not entirely in faith of the allopathic system, but actually in experiences in India, where he had occasion to interact with these systems personally. This life experience or expertise is his ‘toolkit’ to make an informed decision about the use of herbal or
Ayurvedic remedies. This is closely linked – though in a somewhat inverse relationship - to Deena’s adherence to herbal and Ayurvedic remedies. Through her connections to India, via her own experience having lived and worked there, and family connections, information and products would be sent to her. Her ‘illness narrative’ was also intertwined with a range of stories about her experience adapting to the UK, losing her husband to illness and coping with raising a young child.

Some of the themes raised in the interviews have a resonance with what Bury (1982) called ‘biographical disruption’ – whereby an illness becomes a disruptive force in the narrative thread of life, and holds a practical and significant consequence for the social actor. The manifestation of disruption here is often seen in the participants’ talk about how various life events - such as illness, migration and personal changes in life can cause a disruption, an ontological breakage. However within these narratives there are also embedded forms of repair to these disruptions. These occur via the usage of social connections and networks, family connections overseas, or the reliance on traditional knowledges which often stem from having lived in India or Africa, a point developed further and discussed in chapter 7.

The acquisition and use of remedies is also an interesting area for discussion and something which was probed in interviews. Reed pays intricate attention to the phenomenon of sourcing products through what she calls the “transcultural flow of goods” (2000: 3.9). In this thesis it is not just the physical flow of goods, but also the intellectual exchange taking place which is of importance, as expressed in the narrative excerpts. Here, Naresh discusses how a relative in India pointed out a herbal remedy:

*There was an article...in a newspaper which we get from India, and my aunty / niece sent the Jambu powder from India...but you can get this information from Gujarati newspapers here as well.*
Here the respondent(s) are demonstrating how current connections to India, via family and published media (in the UK and overseas) are utilised in acquiring information and products, as well as past experiences and knowledge based on living in the country are being used. This trans-global knowledge and product transfer was not limited to a few respondents, but rather was a major theme in many of the interviews, and is also demonstrated in the viewing of Yoga broadcasts from India.

While respondents often talked of India as both one of the countries of origin, and a place where they visit, it was also seen as the site of a better health status. Often their diabetes and the related symptoms – physical, emotional, social – would improve. There was a generally consistent idea that the body would be able to ‘sweat’ out many of the toxins that were built up in a way which is not possible here in this country (for a variety of reported reasons: cold climate, sedentary lifestyles, diet). Being in India would also bring about more of an opportunity to weave exercise into the daily life routine, rather than relying on carrying out separate exercise functions as people often do here. These things were expressed both in the form of history – ‘when we were in India’, and in the present – ‘when I go to India’. Dhansuk explained:

Certainly the food we eat may not be the right sort of food for this country... compared to India, where you have sun all the time, the majority of the time you sweat it out, here you don’t. There it was more physical. Here sometimes you can be in a mundane job or seated at a desk... or have a habit of eating very oily food very high in fat, in cholesterol etc. For example, ghee or butter, quite a big thing to eat it in large quantities back home in India, but its not so here. The weather, the climate, etc, plus also your genetic build-up – you’re in a different environment altogether. So that’s bound to have some sort of effect on you. Back home you are used to eating full meal at lunchtime, here you are not... they don’t expend that energy, and the whole time they are sitting before the box, whereas perhaps in India you’d be walking, sweating.
However, this reverting to talk of India or country of origin as a place where ‘things were better’ is not always a straightforward ‘idealisation’ of the ‘imagined community’ (Anderson 1991) for three reasons. Firstly, it does not confine the experience to history, but instead locates experiences in both the very recent past and currently, as many of the respondents had been to India frequently since arriving in Britain. Secondly there was an interesting emergence of an awareness of globalisation and urban changes:

*I think there have been many changes in India...the way things were when we used to be there have changed...we think ‘where did all this variety of food come from?’ The more simple your needs in food, the less you can get it. Variety - now in Gujarat, you can get food that comes in from all over India – Chinese food, Mexican food, all sorts. In our day, it was food that was only from Gujarat...people’s income has increased...*(Naresh)

This reflection on urbanisation, industrialisation and related changes is also connected to health and illness states:

*The more research they do in illness, the more diseases they seem to find – I mean, who on earth had heard of diabetes when we were kids?* *(Naresh)*

Some form of medicalisation is indicated here, with the creation of illness definitions and diagnoses related to overall changes in modernity. The possible negative consequences of biomedicine form part of the ‘alternative accounts’ discussed by Stainton-Rogers (1991). The relevance here is that rather than an idealisation of India as a place where illness disappears, it is intimately connected via history and biography to the local community, where these respondents are able to source both information and product according to their needs. Their local community being the place in England where they live, and the location of India as a place which can be sourced as both a holiday visit and information hunt.
This positive health status or improvement in symptoms is not confined to India, but rather extends to the idea of ‘away’ – Sunita talks of her holiday to Spain with her family:

*I really do think that there... in Spain... if you have things like diabetes, you get it much less than here... there was an Indian chap out there who would check my levels regularly, and he’d say to me “it’s only this much today aunty”... many people do say that going there really decreases your problems with diabetes... for example if you’re taking 2 tablets you would only need to take 1... I think in Spain it’s better... weather and things. I mean you still have to look after yourself in everyday...*

While I initially had some expectations of older generation Gujaratis reinforcing the idea of a ‘homeland’ where they are able to best express their needs and live in cultural comfort, whilst reaping the benefit of better health status, many of the respondents here did not conform to this. In the above excerpt Sunita is demonstrating to me that through a linguistic, cultural and ethnic connection even on holiday in Spain it would be appropriate and fitting to ask a fellow holiday maker who was also Indian, to check her blood glucose levels. Far from being passive this widow is able to exercise her limited (by her own admission) understanding of diabetes in order to seek diabetes management help. This flies in the face of prevailing ‘culturalist’ thinking which consistently documents the ways in which ‘high’ risk categories of people – for example ‘South Asians’, do not have the ‘right’ levels of knowledge, or information, and are unable because of language barriers to utilise appropriate resources. What was revealing and important in these interviews is that even in the face of adversity and relatively ‘low’ levels of knowledge these individuals resisted the passive category. They were able to source information, people and levels of confidence in order to manage their illness, via ideas of ethnic belonging. These ideas were shaped not in any concrete sense, but rather according to the contours of their social experience.
Summary

The use of different types of diabetes remedies sourced from allopathic, personal knowledge, and community/social links demonstrates here that far from the picture of 'cultural' pathology rendered by previous discourses of the last 15 years, people in this study utilised the resources around them in a variety of different ways, towards the twin goals of diabetes management and overall health status. While there may not be an overt presentation of the 'ethnic' dimension, as perhaps portrayed by prevailing discourses which seek to identify and target reified strands of behaviour which can be defined as 'ethnic', here we see how respondents weave multiple aspects of their identity into health and illness. This multi-vocality of the experience as manifested in these 'lay health beliefs', prove to be strategic bridges in dealing with the management of illness and the management of the wider network of adversity. Some of these experiences are highlighted in this study in order to contextualise the diabetic experience. The context emphasises that the management of chronic conditions cannot be understood nor investigated without necessarily problematising the nature of existing approaches and taking into account people's already existing skills. These skills lie in maintaining cultural and ethnic connections locally and internationally, through the use of different knowledge systems and help seeking practices, while firmly adhering to the allopathic advice and medicines they have subscribed to as UK citizens. Participants ranged from knowing a great deal about the technical details of diabetes management and calorie intake effects on insulin and blood, to knowing very little of a technical nature. However, even those in the latter group were able to actively negotiate their help seeking in the form of remedies through the use of networks and types of knowledge.

The cultural negotiations demonstrated in the implementation of knowledge about different forms of remedy can be conceptualised as forms of resistance to constructions of passive and pathologised cultural reification. This chapter situates one aspect of the type 2 diabetes experience within a social and cultural context, by exploring what people actually did in the taking of medicines and remedies. The ways
in which localised sourcing of remedies, medicines and information were also connected to wider structures and communities was also an important theme here and helps to locate these experiences within a wider picture.

The following chapter takes this analysis a step further by exploring issues of identity, community, and how people within this sample thought about their social and cultural positions, as they talked to me about type 2 diabetes. The facilitating mechanisms discussed in this chapter and the preceding chapter are connected by individual biographies, but also by a shared experience of migration, difference and adversity which impacted how people coped with health and illness in their life.
CHAPTER 6

DIABETES, BIOGRAPHY AND COMMUNITY

Introduction

Chapters 4 and 5 have explored two aspects of the participants’ experience of the cultural embedding of type 2 diabetes. The process of being diagnosed, anxieties and fears about diabetes and help seeking in biomedical and herbal/traditional forms were all discussed. There is also the conceptual and practical juggling that takes place and the locating of this within a cultural context which emerged as themes. This is central to telling the story of people's experiences and demonstrates how people actually respond to the illness, using varieties of experiences, skills, ideas and methods which are located and sourced in their lived socialities. The underlying current which is weaved throughout the theoretical and empirical substance of this study is that participants, time and again, regardless of the observed socio-economic advantages or disadvantages are playing out active notions of culture and ethnicity, using all the linguistic, faith, migration experiences and tools they have in order to negotiate the social and cultural terrain. People are, as they seem to be indicating here, still not 'cultural dopes' (Garfinkel 1984: 68).

This active sociality can be framed as a form of ‘resistance’, an underlying theme in the emerging data throughout this thesis. These active negotiations of health and illness demonstrated in participants’ talk about how they conceptualise their condition as it is embedded in the fabric of their social and cultural lives can be regarded as forms of resistance to health discourse constructions of the ‘South Asian’ diabetic experience.

In this chapter I further extend this idea with the main focus on how people relate and think about their notions of identity, self and place, in connection to what they do for their condition. This is not an explicit connection between ethnicity, diabetes and
identity. Rather it is a more nuanced relationship that emerges when people talk about their condition, how they have managed it, and the kinds of experiences they have had. Given the age of the sample (generally between 40 and 88), many of the respondents arrived in Britain during a time of great social, cultural and political upheaval, namely the 1950s to 1970s, often experiencing adversity in varying forms including racism. Here the role of biography as touched upon in chapter 1 is important to understanding diabetes contexts. The point of including these as focal issues is that they have emerged from the data as findings which are not just central to this study, but more importantly, central to people’s accounts of their lives. Again, there is a sense in which analysis of these wider experience ‘constellations’ (Mason 2002) provide a more context and sociality driven exegesis of diabetes management in a cultural framework.

Although this chapter presents material in a separate section it is intimately connected with the other analytical themes. However it also presents some distinctive ideas which have both descriptive and analytical threads, and which connect to the overall discussion section. In many ways, identity – the ‘who’ question which people ask and answer in different ways is, if frozen and fixed, a non-sensical notion, because it moulds and changes over time and through space according to certain factors making it therefore contingent and a ‘relational’ (Bury 2005) idea.

In a sense this chapter has been one of the more challenging sections to bring together, principally because it provides a progressive connecting point between the main findings in this study. This connecting point is biography and experience, and the ways in which people employed their histories, experiences and biographical details, which were always located socially and culturally, to navigate their social landscape. The findings chapters have developed from the initial more practical implications of diabetes, to the use of types of remedies. Finally this chapter will address how notions of identity and how they are bound with community and place, result in more conceptual discussions of identity and health. Ideas of how a condition
is managed, thought about, and may impact upon people's lives are here implemented through people's biographical location and the utilisation of fluid identities.

Given that people experience health and illness, and here specifically diabetes in a socially and culturally embedded landscape, the notion of community, place and biography were important in this study. It is impossible and indeed empirically incorrect to argue that notions of identity, community and place, related to life experiences and diabetes management can be separated. Participants demonstrated in chapter 4 that ideas of diagnosis, management of diets and exercise, and everyday monitoring of the illness were also bound up with people's references to culture, connections to family overseas, references to history in India, as well as the current and immediate connections to local communities. Chapter 5 revealed how people used both allopathic and traditional herbal remedies in their diabetes management, but also the combined use of these in terms of general health management. Sourcing ideas and products from overseas was a strong theme and indicated a sense of the local and global (Giddens 1991). This notion of cultural placement - be it related to one's religion, language or history is a prevalent theme in this study, and the use of this 'culturality' as a resource points once more to a more dynamic acting out of social action in people's lived experiences.

6.1 Community and Identity

As shown in chapter 4 within this study the term 'community' is used to point towards a specific collectivity engaged with physically, practically and routinely, such as the local community centre. However a more generalised group notion related to shared religion, language and caste is also involved. An additional dimension that can be discerned is that of homeland – ideas of identity produced and resultant through the processes of migration. In other words, many people in the sample had strong recollections of their histories and lives before coming to the UK, and their identities were in part shaped and influenced by the subsequent experiences they had.
Traversing immediate and extended domains – temporal or spatial – was central to the participants’ cultural accomplishment. Interactions with immediate communities as well as wider networks brought about many outcomes, from advice to products and counselling and help. ‘Community’ here is not to be mistaken for some contrived notion of a Hindu Gujarati collectivity, implying a uniformity and unity within itself, resulting in a version of social closure. Certainly, there are aspects of this that apply, but the term ‘community’ is used as a much more flexible manifestation of people’s social and cultural location. This study was carried out in four locations in the UK, though most of the sample was in two of these locations, Birmingham and Leicester, which had the highest concentration of Hindu Gujaratis. Of the remaining two, Preston, a city in Lancashire, North West England, has a long history of Hindu Gujarati migration and settlement, while the other, Crawley in the South East has a lesser extent of this demographic. Though it is possible to argue that emphasis in a specific place can reveal the relationship between people, community and place relations, there is also the risk that this sets up experiences in one or two areas as somehow homogenous and ‘authentic’, and defends the assumption that by doing so we are ‘tapping’ into this entity called ‘community’. This study in part seeks to break free of contrived notions of ‘authentic’ community and explore just how wide and elaborate people’s own demonstrable ideas of community can be. Malik’s (2005) discussion of culture and authenticity is brought to bear here, his critique being that ‘authenticity’ is a production of Western anthropological quests, where as for people living within the cultures, preservation of culture is a lived and required necessity.

The importance of a critical stance on ‘authenticity’ is also emphasised here through the methodology used in the study. The process of ‘cultural validations’ clearly sets out the elaborate and dynamic nature of the researcher – researched relationship, as one which can be connected by aspects of ethnic, cultural, linguistic, national and faith identity. This however does not mean that through these connections there is an ‘authentic’ relationship that can be guaranteed – rather it posits the relationship as precisely that – a relationship, subject to rejections, acceptances, fluid and broken
continuities, that go towards facilitating the generation of rich data. In this way, the epistemological and ontological underpinnings of the work are closely linked.

Participants in this sample were located within the borders of their UK homes and immediate surroundings, also part of wider collectivities, membership of which was constituted by religion, caste, language and age. As well as often being a part of the immediate community, these wider group memberships within temples and community centres (often the same) formed a source of identity for people with a strong characterisation of inclusivity, exclusivity, and identity.

For example, as described earlier, to have diabetes, or "Sugar no problem" (translation: "the problem of sugar"), the biomedical illness, was an indicator of a common experience in particular groups. The Gujarati phrase "apra man bo che", which literally means "there's lot of it in ours", indicates an 'us' which may provide a symbolic group containment. The self reflexive notion that one belongs to, has membership of, and therefore can to some extent utilise services therein, points to a group which is defined by amongst many other things, the condition of diabetes. This commonality or sharing serves as a binding mechanism in a social and physical sense, for example the attendance of weekly over 50s sessions held in local temples, but also conceptually in terms of identity. When I asked if there was a “community” in the area (leaving the interpretation of the term ‘community’ to the participant), Naresh said:

There’s loads here, lots of Gujaratis, it’s very good. We started going to the Age Concern (events) ...every 2 weeks on a Tuesday we go to the over 50s club, there’s lots of Gujaratis there. There’s even a walking group we attend for those who have diabetes, and there’s a nurse who helps...

Naresh also located ideas of causation within specific groups, here for example:
Punjabi people for example – make everything in butter – we Gujaratis simply can’t digest this type of food... but now even in Punjabi communities they’ve cut down.

There appears to be distinction between different ethnic categories which in the literature has been neglected until recently. The distinction made between Gujaratis and Punjabis for example is both an origin-geographical as well as linguistic and cultural distinction, and is often used to articulate ideas of difference. In actual fact, people originating in the Punjab region tend to be Sikh or Hindu in religious faith, but can be of any faith, given Punjabi is a geographical label, but is often used in everyday terms to denote cultural differences (as is the case for Gujaratis). The distinction in the interview is made not in these terms, but in nutrition and ability to digest rich types of food, calling on older prevalent stereotypes of what it is to be a Punjabi or Gujarati. Here we are presented with both spatial identity and ethnic identity – the particular space used for achieving group-ness via age and diabetes condition membership, and the creation / maintenance of ethnic distinctions via types of food.

6.2 “We became Multi…”

Ideas of group belonging are rarely limited to a single nationality, country or similar entity however. Participants demonstrated that they had loyalties to a variety of identities – and crucially – they were adhered to and could be called upon when needed. For example, Kanti tells me here (within the conversation about her life and experiences) about her role in bolstering faith and security in Hinduism in this country:

Have you heard about the way in France they’re making shoes with Ram\(^1\) on them? First it was on toilet seats, then on something else. So from here, there

\(^1\) Ram is a Hindu deity and incarnation of Vishnu, one of the holy trinity within Hindu religious belief and central to the Hindu epic Ramayana.
was a group who organised a trip, and they asked me to go. I was so furious about this matter. I told them (at the centre/temple) that if you lot don’t go then Hinduism will be buried deep in the ground. They asked me ‘are you going?’ and I said I’ll be the first to go. People appreciate it, it is our community. Even in Muslims and Punjabis, though I don’t too much unless I’m asked to. But in ‘our’ community, I can sort anything out. I’ve done so many things in this country, work of service to people, but I was never happy.

She talks about her undying devotion both to her Hindu faith and to the work of service to others – both being mutually inclusive as ideal states. She explains that as part of her role as a Hindu she must work in the community in the service of others, helping and assisting people, but she must also uphold the virtues of Hinduism as an organised religion, and utilise her skills that way. While this is an emphasis purely on Hinduism, she also goes on to tell me she moves in Muslim and Punjabi circles, but not as much as the Hindu faith. While this may set up a sense in which there is a preferential treatment of Hindus – given this is the faith she identifies with – this possibility is completely confounded by her demonstrable cultural syncrecy:

All my neighbours are Muslim, when they come in I greet them in their custom greeting, and they greet me in my custom greeting. People often ask me “have you changed religion? Or have you made them into Hindus?” and I say to them yes, they have become Hindus and I have become Muslim! This is the only way we are able to live, we have to live with one another in this world.

When I asked her how this came to be and why she felt this way, she explained:

The street we lived in had Hindus, Muslims, different castes, and we all treated each other as a family, always helping, and we tried to make this a daily occurrence...Because you see my father was working under the Europeans, and they used to come to our house to eat, and of course it was a very mixed environment. We kept our customs in eating and drinking, and if
people eat meat then we would be seated separately, but it was always with love. We became “multi”.

It is this ‘becoming multi’ which draws our attention, since the categorisation of homogenous groups is in favour of simplistic and reified versions of culture and ethnicity. This process which many of the respondents talk about, here aptly summarised by Kanti as ‘becoming multi’ indicates that biographies, histories, experiences outside and within the country, aid and inform how people interact on a daily basis and produce their identities. Within this multi-faceted approach is placed the management of health and illness. Examining the fabric of the social context of their illness management points us in the direction of some interesting insights – which might point to what I articulate here as resistances to constructions of passivity inherent in ideas of the South Asian diabetic risk.

This becoming ‘multi’, as expressed in participants’ talk, points us in the direction of conceptualising how health and illness states are socially embedded and culturally negotiated through a variety of utilities. The ‘multi’ process, here expressed as a way of mixing with different cultures, religions, and ethnicities is not confined just to those participants who explicitly used the term. Rather this ‘multi’, a term grounded in the data, an in vivo code, is a symbolic link which represents some important processes in the study. The ‘becoming multi’ can refer to an individual’s life course, and perhaps early experiences through parental exposure to different faith and ethnicity communities, as was the case with Kanti. She employs a network of skills to harness resources, some of these being connections to Hinduism, others more to do with her service work in the community. Her notions of her identity are not limited to or restricted by Hinduism, but rather is part of a wider sense of who she is, the process of “becoming multi”. The connection to her experience of diabetes, and her health in general is exemplified here:

*No problem! If tomorrow someone says to me I have to live in a small hut, then I’m ready. I used to live in a 6 bedroom bungalow built by my husband,*
so when I came here to a small flat, I could've thought “what's this?” But I go according to circumstances...anything I can adapt to. My parents trained me to be that way... I go into the books to see why the headache is there, how should it be dealt with.

The “Multi” making appears to be connected to notions of adaptation and survival, so that there are biographical fibres which interconnect at various points in people’s lives, and in relation to specific phenomena – such as illnesses like diabetes.

Participants talked of how their life experiences enabled them to deal with the vicissitudes of diabetes as a chronic illness. Certainly this is not a notion restricted to particular ‘ethnic’ groups of people. Rather it is a proccessual fixture of biography – the on going work of living creates a life course which is observed, analysed and utilised by individuals owning the life course and researchers ‘working’ on them. This is an important observation here – that life experiences and biographical histories have been revealed to hold many skill sets and enabling structures for the specific and direct everyday management of a condition such as type 2 diabetes. And yet these skill sets are rarely acknowledged, and more rarely linked to elastic ideas of ethnicity and culture.

As Williams (1993) observed through the framework of ‘narrative reconstruction’, accounts often demonstrate the pursuit of virtue and moral accomplishments. In this sense the participants within this study appear to have shown how narratively accounting experience is itself a form of actively engaging the past, present and possible future by creating forms of one’s self – as heard through the medium of storytelling. Through biographies and stories of experience, participants are demonstrating not only possible indications of ‘objective’ events and experiences, but are also indicating proccessual and dynamic account making in action, through stories of adaptation. This is echoed by Scambler (2002) who observes that narratives are cognitive schemes, constructed in time and space, which serve a function of maintaining a coherent whole. Here the coherency required is made more critical
because of the way in which diabetes is embedded within wider arenas of social experience.

As shown earlier in chapter 4, experiences in early adulthood in Africa or India were quite central to forming ideas of syncretism for Harish who talked about his 'professional' circle. His talk regarding 'professional circle' may well have been an allusion to his status within that community, and his ability and position to interact with people. These experiential skill sets that Harish talks about emerged when he was asked how and why he was able to manage his condition in such a way – to which his answer was 'my background'. Similarly, Kanti delved into her background as a teacher in India in order to explain how and why she is able to deal with all that illness throws her way, especially diabetes. Again her biographical features rooted in her early years has great bearing on how she deals with the illness and other aspects of her life now.

In the case of Deena, her early experiences in the UK led her to much voluntary work helping in the South Asian community, cooking, organising and helping in many other ways, and as she explains, this was very much a multi-cultural environment:

Years ago I used to help this centre, even in heavy snow, we used to walk, make food, and help. We never took any money for any of this, it was for the community. Then finally a grant was available, and it grew. At first it was just us Gujaratis, then it grew to Muslims, Punjabis, and it became mixed. They then moved to another area...Well it was too far for me to travel to. So I worked for 2 years after I retired, then I was being charged full tax, even though I was working part-time, it just wasn't fair, this isn't right. I still had a young son, I had to look after him, educate him, and buy things, bus fare. So then I stopped, that was 8 years ago. I used to go and help people, but these days it's a task to help myself.
In her account Deena is linking collective identity and group cohesion in the face of migration to a new country, with the ability and capacity of the embodied ‘self’ – which has now undergone changes due to illness and age – something Harish also talked about in chapter 4. Her connections to groups of people united by ethnicity, religion and language have been lessened because of her personal parenting role as a widow looking after her son, but also by the financial burden of working part-time. Her helping role – something which she talks about with great passion and commitment had to stop and as she explains, the burden of managing her own support is enough of a task.

These experiences are not confined to historical notions of the past, nor limited to memories of a particular geographical place, such as India or Africa, but are very much a lived concept alive here and today. The account reflects a changing process, dynamic with social and biographical activity, and current utilisation of knowledge rather than a snapshot of history. The processes and phenomena discussed in chapters 4 and 5 and as we can see here the integrated notions of pre and post migration experiences as providing a ‘support base’ are related to the notions of identity alluded to here. The sense in which these elements cannot be separated and treated as reified objects supports the thesis that within collectivities and individual lives, illness and health management is taking a dynamic form, through the utilisation of resources available to people. These resources rather than being external to people are weaved into their biographies and called upon to negotiate personal and social experiences.

This demonstration of a multi-cultural layering of social networks is not confined to either the South Asian group or sub groups. As Harish tells me, he has a curiosity and a ‘need to know’ which is part of his overall make-up, but which also informs his diabetes management:

I go everywhere! I go to the church assembly, Gurdvara, temple...Just out of interest...just to know about other people...at the church assembly and
Gurdvara, I talk with them and, many times I can clear up their misunderstanding about Hinduism.

Harish explained to me earlier how it was his ‘background’ and his ‘nature’ to rationally find a way to manage his condition, and that over the 20 years that he has had diabetes he has used this approach to great effect. This practical solution finding however is not limited to diabetes, but rather is part of the weave of both his character – construed as personality and/or psychological makeup – and his social and cultural experience. His ‘nature’ is allied to his positive early experiences firstly in India and Africa, then his experiences of adversity in the early part of his life in the UK. As he explained in chapter 5, dealing with diabetes (especially the types of remedy considered appropriate) was part of the process of negotiating the contemporary social terrain. Harish indicates to me in the above narrative section that his experience of life is not limited by narrow conceptions of ethnic and cultural identity, language or religion and faith frameworks. Rather there is something of a humanist tendency in his outlook, especially when he talks of going to different places of worship and talking to people – and as he says sometimes clearing up misunderstandings about his religion. This is further supported in his talk (and his wife’s comments) about the generational differences that exist between younger and older people:

The old people even now are helpful. The young ones, they’re different. The young generation even our children – well, they’re very different – and your children will be even different from them...I mean at your age you understand family, community, but the other generation they don’t. I mean we mix don’t we, with relatives etc.

When I take this point up with them, it is clear they feel strongly about the importance of the mother tongue (Gujarati), and the lack of priority it is given in the home:

Well, if you don’t speak it in the home, that’s the problem. I mean our kids, we speak Gujarati in the home, and we also go to India every now and then, so
they can understand the language. But the next generation, well I don’t know. I mean the kids come home from school, and they might speak a little with the parents, but unless they teach them the language properly, they won’t speak it properly.

Although these comments are superficially distant from our discussion of diabetes and its management, the discussion about generation, language and community provides links to those social and cultural reproductions which are important for people in the group. The importance of generational links, and the maintenance of language is one part of identity formation which is talked about, and given that the issue of community and identity is part of the landscape of illness management, it provides an insight into peoples lived experiences. While there is explicit confirmation that they have had a long relationship with people there due to generational and experiential links, there is also a generational comment to me, and my generation of South Asians. I am told that while my generation will do things differently from them we have retained an understanding of this notion of ‘community’ and family commitment, while ‘the younger’ generation do not. This is possible because of the language and shared ‘cultural validations’ that have taken place. Here the ‘us’ and ‘them’ is not about ‘ethnicity’, but much more about age, generation and life course. Harish and his wife clearly connect via age, generation and experience with white older people in the area, demonstrated in their affinity with their war time experience, discussed next.

6.3 Adversity and coping

Situating illness experience within the biographical details of people’s lives is important to understand how they might think of diabetes, and negotiate the illness. The phrase ‘becoming multi’ denotes the notion of a sense of multicultural adaptation which existed long before the discourses of race, ethnicity and difference became popular in post war Britain. This adaptation, as the narrative texts above show, indicate that there is a coping style, perhaps even a management method that is used by people to deal with a variety of situations arising in their lives, including diabetes.
This connection is perhaps plausible as a way of linking their experiences of racism and hardship, with the adversity experienced by their neighbours during the war years. The connection is further extended by explaining that while things were certainly difficult in the early days, it was people of Harish’s generation who were helpful:

*It would be one house, and 7-10 people living in there at once. You got to know people, where they were from, who they were. In 1958-60 you couldn’t even find a place to live here, a house. No shop, no house, even if you had money they wouldn’t sell you a house, couldn’t get a mortgage, we’d burn coals in the house and be bathing in the public baths!*  

As with many other studies that examine the experience of chronic illness in people’s lives, this study looks at the location of a particular chronic illness in the everyday lives of people who live with it. A variety of contextual issues emerged in the interviews. For example, when I asked Deena about how long she and her family had been in the country, she talked about how she had been widowed quite early in the move to the UK, and then about her and her families’ experiences of violent racism. She talked about how they had to move within the same city, to different areas because of racism, and other difficult living conditions:

*After my son had been attacked, we moved to x, I didn’t feel safe there anymore. There were all sorts of people hanging around, and I was alone with my young son...we moved and unfortunately there were a lot of ruffians and yobs in the area. When I was working part time, I was coming home from work, and they would shout ‘paki’, and bullied my son at college as well. Then we sold the house, and moved here. Here we’re happy, and have peace.*  

Deena’s interview was often characterised by her sense of adaptation and survival, borne out of her experiences in India, but also the adverse migration settlement experiences in the UK. This was placed in a framework of living which acknowledged
the constraints she was under as a migrant in a new country, and the active cultural negotiations that would be required in her dealings with people from different communities and faith. Through this framework she could manage her diabetes using a variety of mechanisms, as did many of the participants in different ways.

Chronic illness sufferers not only have to live with the physical and psychosocial impact of the illness on their lives, but in the case of ‘minority’ populations, there is the added obstacle of racism and risk of violence in their everyday lives (e.g. Nazroo 1997). These instances show that while health intervention programmes, awareness initiatives and general leaflets go some way in addressing obstacles to health, there are still issues which are part of a broader socio-cultural context which need to be examined in order to assess how people live with their illnesses.

Harish’s earlier mentions of his ‘background’ and how this was related to his time in the UK are linked to his earlier experiences of adversity in the 1960s:

*It was very difficult in 1958 when we arrived...there was no-one here...living conditions were of a sort -- one house and 10 of us in there. But you soon got to know fellow country men...but things were bad – even if you had money they wouldn’t give you a mortgage...bathing in public baths, I still remember the smog and smoke from all the chimneys.*

These difficult experiences were not confined to the past, but were also weaved into much of the character of on-going life here in the UK:

*These are not just early experiences, it’s all the time. You know what is going to happen, if someone gets angry, or behaves sly, you don’t get angry, keep a distance. But it has an effect on your body and mind, and you have to bear it.*

Rather than life experiences being stuck in a past history, here we can see how notions of the embodied self are active and articulated as elements of fluid temporality, and
linked to life as it presents itself in the immediate present. Harish gradually reveals that the holding back of information about him was a tactic crucial to survival in those early years, and formed part of his overall strategy for dealing with life in general. The hiding of one’s knowledge was a survival tactic in the early years of migration which were often extremely hostile environments:

*It’s also created obstructions in this country...if say for example, you try and get a job, you expose your knowledge, then straight away they would say ‘no’ to you. If the boss thinks ‘he knows more than me’, then he’ll try to put you down...*

Harish expresses a sense in which his old identity, the knowledgeable, influential self has had to remain repressed, or hidden from general view. For the sake of ‘fitting’ in and surviving in a new country, he has had to hide from view his expertise, qualifications, and knowledge, for fear that it may threaten the security of those who employed him, and generally those around him. Harish demonstrates how using his biographical history, background, and ethnicity to move between cultures, religions and languages, he has been culturally negotiating a changing landscape. This strikes a resonant chord with Charmaz’s (1987) interactionist based research on the changes to the self which can occur as a result of chronic illness. Moreover there is a possibility of repair to the fragmented identity that can take place, shown in this study perhaps by participants talking about former experiences, and how these impact on their immediate and current experiences, both within and outside of the diabetes context.

The connecting of diabetes to this negotiation is sometimes carried out explicitly, for example Deena talking about how because they had lived in India, they ‘knew’ how to deal with herbal remedies, and Kanti’s experience of being a teacher allowing her to find out information about her condition. For other people in the study however the connection was less obvious, but still apparent – for example Harish’s talk of ‘background’, and ‘professional circles’, connected with his insistence on not using any herbal or traditional methods that had not been proved, seemed to indicate that he
was employing his biographical context and experience to the immediate condition. As Chamberlayne et al (2000) have argued actors do not always recognise certain aspects of social reality in everyday life, and that the symbolic significance of interactions are not usually understood in the routine nature of this everyday-ness. This of course echoes the phenomenological paradigm and life world approach used therein to theorise social reality, which distinguishes between social actors giving meaning to experiences through the use of common-sense constructs, and researchers interpreting these phenomena (Apitzsch and Inowlocki 2000). As emphasised within this study, the role of 'structures of relevance' (Schutz 1962) gives an indication that biographical contexts are employed in making sense of the world, and used in ways which allow the management of conditions like diabetes in a taken for granted fashion.

Coping with an illness then may well be part of the overall panoply of life events which people need to negotiate and deal with, especially when there are a range of difficulties relating to race and racism to manage. Some of the people in the sample were able to relate their experiences of adversity to their management of their diabetes, health and illness in general and their bodies, while others did not specifically emphasise this coping strategy. For people like Sunita, adversity was indeed a part of everyday life, and being a widow, living alone and in an area where she shared language or culture with few of the residents, diabetes was another situation to deal with. However, as shown in earlier chapters, this has a bearing on our current discussion of biography and identity. Despite the obstacles, Sunita demonstrated that embedded in her everyday living are mechanisms for managing adversity, such as visiting the local community centre. This is something she is unsure of but feels is beneficial, visiting the local 'Indian' shopping area where she can meet with people and talk, and as shown later, her religious faith framework. Within these layers of resources, which are utilised in various ways at various times, diabetes is one of a range of problems that need to be addressed:
I never used to go much but people said to me I should go, meet people, learn things. These days I do go...There are people there, you can meet them, see their faces, it makes your heart happier, and you can have a nice time, talking to people... There are no Indians here. But having been here 25 years, I'm used to it. Sometimes I go to Coventry road, sit there, and meet people... For the last 8-10 years, I've not taken sugar in my tea, no other sweet stuff; you have to take care of yourself. People at the hospital often tell me that I look after myself, and that I have courage. Sometimes it does get bad, but that's the way it is with diabetes.

I always go outside. Afternoons I'm always out, I do my prayers, then cook whatever I need to and then leave the house for a while. Even if it's not nice outside, and I'm feeling unwell, with headaches and dizziness, I still go. Because a little fresh air is good for us. But then if it's really bad, I do have a rest, and sit. Even when I go shopping I do it myself, I don't like to harass anyone, my kids, because they do their own, though they get me the larger shopping stuff, but all else I do myself. You have to have some courage and do things yourself — if you don't, who's going to do it? In this country, you can never say that my kids don't do enough for me, that's wrong, they are also busy, with work, their own kids at school, and they don't have time. Weekends they have their own shopping, so you can't say they're not doing this and that. For that reason whatever one can do for oneself, one must, just maintain courage.

Embedded within Sunita's account are numerous themes, connecting her methods of dealing with her social landscapes, from getting exercise, socialising, maintaining her diet, to talking about the need to be as self sufficient as possible, given the generational and lifestyle differences between family members. This of course strikes many resonant chords with the documented experiences of migrants to Britain in the early post-war years (Visram 2002; Ballard 1994). These facets were only revealed when Harish's diabetes management strategy was revealed in the interview, and
demonstrates pertinently how biographical and ethnic identity issues can be inextricably wrapped up in how an individual deals with their illness. Weaved into the biographies and cultural and ethnic identities there are some revealing insights about the interaction of structure and agency, regardless of the ethnicity of the individual. This question, at the heart of the sociological endeavour can be addressed in part by looking at some of the themes emergent here. We can get a picture of the relationship between the individual and society by explaining some of the interactional elements of the health / ethnicity connection.

These however are not simplistic, oppositional binary relationships. There is an interesting juxtaposition between the categorisation of a hostile indigenous white community versus the support and familiarity of "fellow countrymen" who Harish had gotten to know during early experiences. Harish invokes the use of generation and here it is instrumental in showing how simple notions of group belonging are not useful. Harish’s connections can be seen as grounded by the common experiences of adversity faced by both migrants coming into the country, and the English white populations who lived and survived during the second World War. The street and local area where they live have a mix of people of different ethnicities and here they (his wife joins in) talk about this:

(Neerti): We know all the people around here, the old people. When I first came they helped me a lot and in those days, always helpful, always asking if we needed help. The old people even now are helpful. The young ones, they're different.

(Harish): that generation is different. Second World War, that generation, they know what difficulty is.

In the above excerpt, there is a useful and interesting exploration of the nature of their relationships to the local and older, English people in their area, but also a nuanced and subtle indication of generational connection.
Adverse experiences such as racism have of course in some sense a life of their own in terms of analysis material, and the plethora of research detailing people's experiences give an indication of how powerful these experiences can be. However, detaching these from the other facets of experiences supports artificial categories of analysis, rather than encouraging context driven insights. The starting point of the study was to investigate how people managed and dealt with type 2 diabetes whilst negotiating the cultural and social landscapes they occupied. In order to do this, this section has thus far discussed the importance of flexible ideas of community belonging and the way in which people employ their life experiential skill sets, formed by biographical processes, to deal with adverse experiences. These are of course not adjunct to the discussion of diabetes, but rather weaved into the fabric of its social and cultural placement. As the underlying theme of the study suggests, these active articulations point to participants employing a form of 'resistance' to constructions of South Asians as passive and vulnerable to particular risks.

6.4 The role of religion

The study sample were Gujarati people, mostly of the Hindu faith, and most were located and approached either through local temples / community centres and through a popular cultural and religious event. This runs the risk of making a set of assumptions: that all the people in the sample are followers of the same faith; that it was not necessary to look beyond these locations, employing a 'one-size-fits-all' stereotype; and that religion would not be a discussion point in the interview since it was a taken for granted entity. However, none of these 'research risks' were left unattended. While accepting that most of the people in the sample were Hindu, it was noted that one individual was Christian – a fact only uncovered during the interview, and nearly overlooked because of the physical context of the interview – it was during a large scale public event where a venerated holy scholar of the Hindu faith was visiting. Religion here is not used in a narrow, categorical sense, but as an example of cultural context. The physical and social borders created and used by people was an interesting element here. Whilst aware of the importance of place and identity
relations, there was also an awareness of artificial notions of ‘community’ and place limited to one temple where people might gather, and become the researcher’s focus. Religion was indeed not raised by me in any of the interviews, except one, but was mostly raised by the participants themselves, as shown below. The one person who was asked the question was considerably younger, and this therefore may have had some bearing upon my likelihood to ask a question. This may of course have some connection to the on-going project of late modernity, whereby aspects of identity are questioned by every social actor (Blaxter 2004) and being of a younger generation it may have been easier to approach this topic with Rina and a little more difficult to raise these questions with the older members of the sample. The difficulty with raising the issue of religion with the older participants may have been related to researcher / researched identity politics. Given the considerable age difference between myself and most of the sample, to question the role of religion – however ‘neutrally’ or ‘objectively’ may have run the risk of sabotaging the relationship thus far created. In many of the participants’ lives religion played a substantial role. Sometimes this was clearly evident – in the form of religious pictures in the home, or a small shrine or worship area, whilst at other times it was less clear or immediately apparent. I decided to make a decision not to probe or ask questions about this unless it was raised or hinted at by the participant. There is of course always the possibility that I was wrong in this caution, and should have probed further in this area.

Within this sample three women explicitly talked about religion as a personal experience, and one man talked about it in general terms. Although I was interested in finding out about the role of religion in the management of diabetes, I was also aware that much research has been carried out in the field of spirituality and health, and the study could potentially bear more fruit from its other areas of enquiry. However, the role of faith and religion was inherent because many of the participants were identified and / or approached either at or through the local temple / community centre. In one site, the duality of the specific location was interesting, since there was no explicit revealing of ‘religious-ness’, and therefore there appeared to be a ‘secular clause’ available to attendees of the centre. For those requiring explicit religious
devotion, there was a fully functioning temple, where people could go and worship. Two of the three women who talked about religion had strong ideas of how much help and support they gained from their religion. The third who was approached also talked of religion but with a lesser slant on organised religion. Here the women speak:

I was never worried. Once I had 5 complications in the stomach, a serious operation, and I was unconscious for 9 days. At that time I saw a big light, I have a memory of the light, and even today when I remember it makes me happy. God is with me, my faith is strong. Whenever I have a question or dilemma, all I do is pray overnight and the next day I usually have an answer. (Kanti)

I’ve just let God take care of my illness. Diabetes, arthritis, I have it all. Still, I’m ok. God keeps me well. Without the grace of God, nothing can happen, he controls everything, so I just put faith in him, and he takes care of me, and gives me courage. Wherever I go make sure you bring me back home safely. I pray for 1-2 hours a day, I used to go upstairs for that, now I pray here downstairs. I get courage from God, and I don’t feel alone. I’ve been here 25 years, and there have been burglaries everywhere around here, except here (my home). (Sunita)

I’ve always been quite spiritual, I’ve always believed, and I believe in certain things and that’s where my strength comes from. I don’t pray everyday, but I’ll say a little something. We don’t go to temples, we have one at home. To me God is everywhere; you don’t have to go to a specific place. (Rina)

The role of religious belief then is not an all encompassing ontology which operates exclusively but rather, in the context of participant’s lives, works with and between other support structures. For Kanti while describing unshakeable faith, the life lived well and virtuously is one where the individual utilises all around herself for the purpose of doing good – this automatically includes self preservation, survival
through adverse circumstances and proper management of illnesses – as she stated: “You have to be your own doctor and treat your body in a way which pleases you”.

Of course the way in which any support structure is utilised is contingent upon an individual's position in advantage / disadvantage in society. Sunita, a widow living alone in a terraced house in a district of Birmingham has had troubled relations with a white male neighbour recently, and clearly feels that the area has not improved with the passage of time. However, her steadfast beliefs in religion provide her with comfort and a life management system. Belief in Hindu deities, as well as of course an overall Hindu God allowed Sunita to functionally take care of her health and illness states adequately. In her account, she explained that “doctors are the experts”, but it was only through God that they were able to utilise such gifts. Faith for her then was also a conceptual and ontological linking mechanism that allowed her to act and react in accordance to her bodily, social and cultural environment. As described in chapter 4 and 5, she was able to interact with people in the Hindu Gujarati communities, attend community centre events, buy medical equipment to monitor her blood glucose levels and seek help from various professionals. While she was anxious about her illnesses, including diabetes, she relied on her faith to “bring her back home safely”.

In a way similar to the use of herbal remedies and cultural knowledges her religion provided a method of finding solace and comfort whilst at the same time functioned as a cultural reproduction and maintenance tool, used to maintain a religious, but also a ‘healthy’ and ‘virtuous’ (Blaxter 2004) identity. However, leaving diabetes to God is not an indication of fatalism or passivity. On the contrary, it acts more like Schutz’s (1970) zones of relevance – as a support mechanism which increases the likelihood of actively negotiating health and illness, through whatever means is possible for her.

The more generalised spiritual definition of religion or religiousness is subscribed to by Rina and this may be a function of her age, as at 40, she is considerably younger than the rest of the sample. However the commonality lies in the support structure of belief and faith. The other major difference is the absence of a site of religion – again
perhaps an indication of late modernity's response to the grand schemas of modernity; that a younger generation may not rely so much on specific buildings and sites of religion to engage in spirituality. This is not a focus of this study but alludes to several potentially interesting areas for research touched upon here.

The point of inclusion here is that though only three people explicitly mentioned their personal ideas of religion in the discussion concerning diabetes management, there is a demonstrable utilisation of cultural resources here, important for any query regarding how people accomplish illness and health management. The existing community centres which provide meeting points, lunch, health education talks and a social focus for the people here is evidence that the religious framework is a useful tool for collective mobilisation.

While Kanti explicitly employs what might be called a 'dual support structure' of religion and societal devotion – actively managing her diabetes to survive so that she can continue her work, Sunita operates the 'fall' back position of religion, where her faith is a safety net against what she sees as adverse life circumstances. Rina's general and less traditional spirituality invokes similar ideas to Kanti, but without the explicit characterisation of Hinduism. All three of these frameworks work as cultural tools, embedded within peoples' lives, but not restrictive on how people think and manage diabetes.

The fourth participant who talked about religion, Kishore used it as an extension of his 'diabetes as metaphor' theme. This is of course my application of a thematic characteristic, utilised in order to identify, characterise and know better the individuals within the sample. As shown in chapter 4 Kishore was fond of telling me how he tries to help people in the community by using different metaphors related to different aspects diabetes. The various eye problems that are associated with diabetes (cataracts, glaucoma and retinopathy) are explained by his comparison to spilling Lucozade:
When you spill Lucozade somewhere what does it feel like after a while - sticky right? So if your blood is Lucozade, and there’s too much sugar, then you get the same effect - sticky. Our blood vessels get sticky, when the blood flows there is too much sticky deposit. I explained to them that we have certain nerves, and we have our ‘Lucozade’ going to them, and the walls of these end up sticky, so when we try and focus our eyes, it won’t function, the reaction will be slower.

Negotiating calorific intake he compares to ‘balancing your books’, an accounting term he is familiar with and tells me is a relevant metaphor that can be used in the Hindu Gujarati communities:

I say if you want to eat something you should do, but you must balance your books. If you’ve eaten too much, go for a walk.

Similarly, he talks about religion as being a prescriptive guide to good moral behaviour and outlines how religion needs to be used as a set of guidelines for people to manage their daily lives:

Religion...it’s like a teacher in a class, provides discipline. It’s something we have to respect. I respect all the religions, I’m not deep, and I’m not very religious. If we sit and listen to these hymns and preached sermons, do we follow them? There are lessons to be learned.

The choices people can and do make within the boundaries of social contexts that contain / restrain activity are moral as well as practical. The morality is often found in religious frameworks and can hence be related to illness experiences. For example the statements “I have diabetes but God looks after me”, or “I have devoted much of my life to serving others in society – that’s Hinduism” offer an idea of the interweaving of illness management of diabetes and religious / faith ideas.
Although all of these participants talked of faith and religion as powerful support mechanisms, they also all demonstrated that their religious ideas were embedded within a wider social fabric. Some of this fabric is illustrated in previous sections, while other still is described below. Contrary to some research carried out in South Asian communities — which depicts people as passive and fatalistic recipients of religious belief (Naeem 2003), here people are reflexive co-producers of social action. Religion is part of their overall framework for dealing with diabetes. Using religion as one of many resources led to a multi-faceted interactional model of their daily lives, rather than a unitary model.

Summary

Within participants' socialities there is complex set of relations between the local and global, the immediate and extended environment and the past and present. These dialectics also extend to notions of how people located themselves in terms of self identity. Although all participants regarded themselves as Gujarati, they all utilised a weaving of multiple identities — again for social accomplishment but also for the purposes of diabetes management.

The multi-vocality with which participants expressed their notions of identity within their social and cultural experiences was also extended beyond both physical and conceptual borders. Through talking about managing diabetes and community interactions they were able to negotiate a range of experiences using the cultural and ethnic resources they had available — which included biographical and life experiences.

Chapters 4 and 5 presented data which demonstrate the active negotiations of health and illness, as people come to terms with the diagnosis, and find ways in which notions of passivity are bypassed. Their cultural ethnic identity frameworks were employed to deal with their illness as a lived and embodied occurrence. The kinds of remedies, medicines and balancing of nutrition needs are also presented as complex
webs of interaction whereby people reflect upon the impacts of nutrition and activity on their diabetes, but do so within the structures of their own life histories, narratives and experiences. This chapter is a further move along the continuum of socio-cultural experience and diabetes. Notions of identity and place as lived entities were weaved into the diabetes experience and situated the accounts in relation to other structures which are used to buffer the diabetes experience. Connected to these were other structures such as religion and faith, experiences of racism, and links to people in the community.

This continuum can be seen to demonstrate a number of underlying themes running parallel. People’s social and cultural activities within the management of diabetes can be identified as forms of 'resistance' to the constructions of passivity and cultural pathology as have been maintained in much early research and literature and various examples of current work. These resistances as articulated in this thesis are demonstrably manifested as active negotiations of health and illness and more accurately, cultural negotiations. The findings demonstrate that within their lived social contexts, participants were using the resources in their life histories, experiences of adversity in migration, and their experiences in their ‘origin’ countries, as well as their current and immediate connections to communities around them, as enabling and empowering structures.

The following chapter brings these analytical strands together and provides a theoretical backdrop to them, so that the wider arena of health, culture, ethnicity and identity can be discussed.
CHAPTER 7
THEORISING THE EXPERIENCE OF DIABETES IN A SOCIAL AND CULTURAL LANDSCAPE

Introduction

The findings reported and discussed in chapters 4, 5 and 6 have described in some detail the ways in which participants’ talk and activities within the health and illness arena are embedded in social and cultural contexts.

This chapter will bring together the strands of data already presented and situate them within a wider theoretical field. Ultimately the goal of this research is to make an empirical statement, a qualitative data driven argument about people's experiences of type 2 diabetes within the continuum of ethnicity, culture and identity. How this worked out in both planning and practice was partly discussed in chapters 2 and 3, but the effects and impacts on the research will also be discussed here, as it underlines the interweavable nature of identity.

One of the aims of this research has been to address the need to re-theorise ethnicity and health, or at the very least bring notions of theory back into the arena of health research. By simply describing observed differences in either characteristics and / or behaviour, health research in ethnicity has seldom offered possibilities of explanation. This trend is exemplified by various research studies (Naem 2003; Hill 2006; Department of Health 2002) and which indicates that observed differences in health can be taken as explanations for differences, seems not to have abated. There was a constant need in this study to ensure that whatever empirical finding was generated could be then situated within some form of theoretical fabric. Participants’ accounts of their experiences had commonalities with each other, as well as differences between them, but they could be seen to symbolise broader processes. Reviewing social epidemiological evidence and health research studies in the area of diabetes in the
South Asian communities, it is possible to discern a construction of a particular South Asian ‘risk’, which relates to the supposed genetic, cultural and lifestyle factors that people in this group are characterised as being at risk of. At a methodological level, the process of ‘cultural validations’ in this study characterises interconnections between various facets of identity occurring within the field. Rather than mark this as a static and delimited ‘box’ within which difference is ‘dealt’ with, this process points to a wider acknowledgement and embracing of the notion of cultural identity and ethnicity as pro cessual contexts, which cannot be limited to encounters but characterise whole research contexts. At the empirical level, the findings generated within the study confirm what qualitative sociology in health and illness has been telling us for a number of decades – that in investigating states of health and illness, there is always a requirement to look outside the individual and observe and locate those structures which impact upon the person’s life (this is clear from early work by Blaxter 1983; Herzlich and Pierret 1987). What people were saying about their diabetes necessarily has to be placed in a social and cultural context, with specific reference also to ethnicity, life experiences and history. This placing of experience within a wider temporal and spatial location allowed the research to go beyond merely descriptions of states, and move to analysis of processes. For example, it represents one dimension to describe what people feel and then do about their diabetes, but represents a different dimension when these same people talk about how their management ‘tools’ were developed, where they acquired information and what kinds of connections they still had with the countries they migrated from, as well as their personal locations in history.

By harnessing the process of cultural validations, and utilising the resulting access to and rapport with participants the study was able to generate rich data. In this research because of the intersections between my various identities (manifested in cultural, linguistic, country of origin forms, as well as appearance) and the participants’ identities, the relationship was rendered in terms of linkages. These linkages were framed not in terms of an essential correspondence of ‘sameness’, but rather in terms
which could be compared to Goffman’s ‘wise’, and the participants having an ‘own’ identity (1963 cited in Oguntokun 1998).

Finally, the research here has aimed to connect individual and group expressions within their accounts to wider processes and theories. Showing how a participant takes information about diabetes remedies from the GP and the pharmacy, and combines this with advice from her local community, and her connections abroad as well as her experience in the past can be indicative of a wider process of ethnic and cultural identity formation and maintenance. This list of course is not exhaustive – as the data show this is extended to the use of herbs in cooking and the management of calorific intake within social settings. Rather than see these demonstrations of action as static and fixed, we can within this study situate them in a wider context. The use of herbs and traditional remedies comes about not simply as a taken for granted nugget of information, but rather as a socially, culturally, historically and temporally maintained interaction which works with biomedicine and not against it. The mediation of food intake – amount as well as type – is also something which some health discourse has a tendency to render a subject of ignorance and pathology. Minority communities are either ignorant of the ‘facts’ regarding what is good for them, or at the other extreme are abusers of this information and refuse to ‘comply’. Again, this study has shown that people are clearly not either compliers or non-compliers – but rather engage in the negotiated order of social and cultural interaction. Situations are assessed, reactions are gauged, connections to a community, family, or individuals are metered and the action of participating is contingent upon these cultural processes.

There are several threads which need to be integrated within this discussion. One is the nature of the findings with special reference to diabetes management and the generation of data to illuminate this experience. The second thread is that of cultural and ethnic identity, and what exactly can be elucidated about culture, ethnicity and identity by exploring the lived experience of diabetes in these communities. By weaving these strands together, it is possible to generate a theoretically informed
impression of health and ethnicity which is driven by empirical findings. Placing these findings within the sociological lexicon is one aspect of this task, and given the many elements of the findings which have points of intersection with established sociology of health and illness literature this is a required and useful task.

We can also locate the findings within a theoretical context for examining identity, ethnicity and culture. As already discussed, there is a danger within research on health and ethnicity to restrict and fix notions of what culture is, so that reified ideas of people are used in research. This results in the pathologisation of minority cultures where the use of stereotypes about 'cultural traits' attaches a series of fixed behaviours to groups of people. Locating this work theoretically can allow a more informed and insightful approach to health and ethnicity. Within this study the aim is to situate people’s experiences of diabetes within notions of cultural and ethnic identity. Consequently what is being offered is an explanation of how people manage their health and illnesses, within a social and cultural context. It is only by allowing people to talk of their migration histories, their current connections with local and international communities, their knowledge in herbal remedies and traditional medicines and their dealing with adverse circumstances that it can be possible to situate accounts of health and illness. As the early work of Herzlich (1973) demonstrated, when people talk about health and illness, they are also talking about their social and physical environment. This is similar to respondents in Williams’s (1984) study on rheumatoid arthritis who added a moral (and political) component to their accounts which aided the process of linking aspects of the body, self and society.

The following sections will now discuss these ideas and their relevance to the thesis.

7.1 ‘Lay’ ideas of health and illness

Many aspects of the findings in this study relate to elements found in the now established medical sociology literature of lay health beliefs. We can place these experiences within the lexicon of lay experiences, widely discussed in many studies.
over the last quarter of a century and the subject of recent state of the art reviews (e.g. Lawton 2003; Pierret 2003; Blaxter 2004). Given the fact that this study aimed at gaining an insight into the socially and culturally situated experience of diabetes, it is necessary to acknowledge and attempt to understand experiences from the participants' lived perspective, as well as construct an interpretation of what might be happening both in the production of narratives and the things these narratives point to in terms of experience. As Kelly and Millward (2004) state, this body of work has been important because it gives a voice to the patient experience, and introduces subjectivity into the discussion of illness.¹

The role of the lay person's actions in health behaviour has been important to the findings in this study, given they include the central themes of managing diet, exercise, diagnosis, life style routines, medication and the use of complementary therapies, such as traditional medicine and herbal remedies. There is of course now a long established history of research which suggests that lay health beliefs, or expertise has its own logic and internal consistency which people put to use in their every day lives (Calnan 1987; Calnan and Williams 1992; Prior 2003; Popay et al 1998). There is also some debate, engaged by Prior (2003) about the use of the term 'lay expert' – and its appropriateness. Prior argues that the crux of this debate is the difference between the terms 'knowledge' and 'beliefs' – where knowledge of an applied nature may be acquired and used by an expert, beliefs are seen to be simply held. However, popularity of the concern with the ways and means of lay people has clearly been a driving force for medical sociology, such that the emergence of the 'lay expert' (Prior 2003) is apparent. This notion of 'lay expert' is however contested, as Prior (2003) states, lay people are not really experts – even though they may have some expert knowledge, training or experience. Rather, as Collins and Evans (2002) point out there is an oxymoronic value to the term 'lay expert', and giving a lay person the label

¹ This subjectivity is seen as direct resistance to the objectification process Parson's sick role contributed to (1951), although this does not take into account the agency-structure notion addressed by Parsons in his work on psychoanalytic processes and the relationship to society (see for example Figlio (1987), Lupton (1997)).
of ‘expert’ can be reckless and dangerous, given they can often be wrong about the technical intricacies of illnesses and conditions.

Most of the participants used a combination of medical knowledge with traditional remedies. However these lay ideas are embedded in and utilised with social and cultural resources to produce a health outcome, and as such are more complex than a simple binary ‘lay / professional’ dichotomy allows.

As Shaw (2001) has argued, one needs to question the ‘lay-ness’ of lay health beliefs, and instead of blindly accepting the notion, we should question what precisely we mean by applying labels and categories to groups of people as ‘lay’. This allows us to identify a conceptual tension in this debate, especially given the applied nature of sociological studies of diabetes experience, and question where exactly the lines exist which demarcate ‘lay’ and ‘expert’ notions. Whether the people in this study are ‘lay experts’ or not is a debate that may continue; this is not of primary concern here, rather the people in this study are ‘experiential experts’, with intimate knowledge of their bodies (Busby et al 1997), their social surroundings (Williams 1984), and their cultural placement.

Knowing about traditional medicines and herbal remedies was not simply about ‘lay knowledge’, but an accomplishment of cultural maintenance and reproduction. To know that certain roots and herbs have specific effects on the various bodily mechanisms and operations which could contribute to better diabetes management was a system of skill and knowledge passed inter-generationally and internationally. This global and local health positioning may be characterised by ‘lay’ knowledge, but is more fundamentally a demonstration of culturally located health and illness management through personal biographical and social resources.
7.2 Linking individual and group processes

While research in this area has used ‘critical’ ethnography to explore the variety of contexts and ways in which traditional, or ‘desi’ practices are used (e.g. Hilton et al. 2001), they tend to lead to a rather general, prescriptive statement, along the lines of ‘cultural sensitivity’. While of course adhering to the need for reflexive and sensitive approaches to an increasingly diverse health care needs base, there is also a need to move beyond this result to make a statement about what these uses, practices and contextual encounters may symbolise and mean – both for the user, and wider society. Having a more theoretically led approach can bridge the gap between crude multiculturalism and insensitive health care approaches. In this study, although there is a description of what people use in terms of herbal remedies or alternative and complementary practices, there is also an importance, as Eade (1997) argues, to demonstrate what these products and practices come to symbolise. They can point to a range of social, personal and cultural processes concerning how specifically diabetes is conceptualised and managed, and more generally health and illness states are attended to. Crucially the additional facet of this is that it also provides a link between the individual and society – the agency structure question. Studies that look at the use of herbal practices – the intellectual product in the form of the knowledge as well as the physical relationship involved in getting hold of the products are useful for rendering a picture of the pliability of individual and group processes working within wider social and structural constraints. Giddens’s (1982) notion of ‘resources’ is useful here as a way of conceptualising knowledgeable actors drawing on structural properties in interaction, though in this study the resources are also systems of knowledge embodied and embedded in cultural history and experience. As with Reed’s study (2003) the syncretic use of remedies in this study was characterised more by the use of products than the use of plurality of services. No-one in the Hindu Gujarati sample mentioned separate, alternative or even complementary services, although these do exist in both of the larger city areas of the study. Rather the use of these herbal remedies and specific health-enabling vegetables and products were embedded within personal and biographical frameworks, mediated by both individual
and collective histories, which would be then the subject of public and social accounting during the interview. This means that while individuals felt that these systems of knowledge were personal to themselves, they were also aware of these ‘knowledges’ (Worsley 1997) as membership markers, symbolising group membership to an ethnic and cultural collectivity.

7.3 The relevance of biography

There are a number of established, useful and important ideas which assist in placing the experiences of people in this study in empirical and medical sociological theoretical terms. These strands are firmly embedded in the arena of medical sociology and while new and innovative forms of insight may be on the horizon, these existing frameworks do provide core concepts to understand the key issues here. Chapters 4, 5, and 6 demonstrated that participants’ accounts which were organised into the three main thematic areas, showed embedded and embodied social practices, striking many resonant chords with a number of established frameworks in the sociology of health and illness. In particular notions related to biographical work were evident.

Bury’s notion of ‘biographical disruption’ (1982) can be applied in a general and conceptual sense to much of the participants’ experiences, given the way in which they experienced a disturbance of those aspects of life that were taken for granted. Using Giddens’s (1979) ‘critical situation’, Bury emphasises the way in which a chronic illness forces a re-thinking of a persons’ biography. The forms of disruption that take place when a person has diabetes are various, for example, learning how to monitor blood glucose levels, learning to ‘read’ the body’s signals, engaging in analysis of diet and nutrition, connecting with sources of help. As Bury argues, the disruption can be both to practical aspects as well as to structures of meaning. This can be linked with the experience of diabetes, and the experiences of people in this study, as highlighted by Kelleher (1988). For diabetics then, illness changed their self concept, and for the maintenance of biological harmony a specific form of routine
needed to be in place – one which sets them apart, leading to what Kelleher (1988) called ‘loss of spontaneity’. These elements have core connections with the way in which a diabetic may lose a ‘sense of self’ (Charmaz 1983). However although the participants in this study talked about how their lives and routines had changed, explaining their anxieties and uncertainties, on the whole they did not emphasise the disruption. It seems that participants a) did not experience the extent of disruption that another illness might bring, or b) did not talk about the full extent of the disruption in their narrative accounts, given as Mattingly (1994) suggests that stories, or life narratives are made as well as told. Because the diabetes is manageable, and a form of body-harmony and physical maintenance is possible with type 2 diabetes, there may well have been a ‘real’ sense in which the diabetes was one aspect of the totality of experience, so they did not seem to experience a biographical disruption in the strictest sense. As Pound et al (1998) reported it may not be a disruption but more a continuity through which other facets of their lives had been experienced, providing a useful insight into some of the emergent data here. Rather than conceptualise diabetes as an event provoking ‘disruption’ the accounts of participants seemed to invoke more a sense of a health-challenging event which needed to be dealt with using various culturally and socially embedded resources.

As Williams (2000) observes the concept of biographical disruptions is centred on ideas of ‘normal’ versus ‘disruption’, setting up a binary experience of chronic illness and can fail to account for ‘normal crises’. Similarly, locating sociology in the lived temporality of illness experience (as this study aims to do with its focus on what people do now) as well as linking this to experiences in their history is crucial to analytic insight – a point Kelly and Field (1996) also make. That contemporary life in the west is characterised by social structures which are less determinative, allowing for more flexibility and therefore facilitating wider expressions of what is ‘normal’ and what is ‘disrupted’ is a feature of modern life. It is conceivable that for the Hindu Gujaratis in this study, over a period of time the nature of type 2 diabetes became a ‘normal crisis’ which was part of both the ageing process and a part of the general task of managing other structures in their lives.
Similarly, in Williams’ (1993) coining of the phrase ‘narrative reconstruction’, there is a quest being demonstrated within the narrative accounts which highlight amongst other things, a pursuit of virtue and need to establish ‘moral accomplishments’. The strategies people adopted in maintaining a moral and virtuous self, for example by attending weekly events at the community centre / temple, by assisting and advising those people around them in similar circumstances, and the passing and maintaining of herbal and traditional remedies to subsequent generations could indeed be considered as narrative reconstructions – if we take for granted that there is indeed a discrete ‘reconstruction’ that is needed. These concepts are useful here because they locate the experiences and activities within biographies and wider experiences of society thus establishing a relationship between health and illness, identity, culture and wider social forces.

For example, as with both types of diabetes - insulin dependent and non-insulin dependent - the monitoring of food and drink intake is an essential part of the regime, so that a ‘balance’ can be attained in blood glucose. The participants in the study – some of whom did not speak a great amount of English, were widowed and elderly, and suffered from other conditions such as high blood pressure and arthritis – were all producing accounts of active engagement in the diabetes management and stoicism in the face of suffering. The ways in which many of the participants who were living with family had brought their involvement into the circle of experience did not reflect a strong sense of disruption, although the fact sometimes there was a family support system around them may have contributed to the management. Similarly, the ways in which herbal and traditional remedies were used alongside biomedical systems in syncrecy suggested that although there may well have been a biographical blip when diagnosed with the illness, the telling and demonstration of what people did using these systems of knowledge, was reflective of active and pro-active engagement with biological and social environments. Even the diagnoses in several cases were ‘double checked’ using doctors in India (during holiday visits), while information via newspaper articles were sent between countries as evidence or counter evidence for a medication’s side effects.
The idea of 'biography' has also been used by Carriabburn and Pierret (2002), in their use of Corbin and Strauss's (1987) phrase 'biographical work'. This refers to what an individual needs to do when faced with a chronic illness. In Corbin and Strauss's formulation, 'biographical time', 'conception of self' and 'conception of body' are arranged components which go to make up a biography – it is piecing these together which requires biographical work.

Although 'biographical disruption' has elements which connect to the data here but does not appear to be a key conceptual framework in analysing the experiences of diabetes for this study, there are also constituents in the now established sociology of chronic illness panoply which have relevance for the major themes in this study. Charmaz's (1983) 'loss of self' thesis an interactionist line explored the way in which the self becomes disjointed and fragmented, leaving behind remnants of the once valued persons' self-identity. This however could be repaired in what Charmaz (1983) has termed 'reconstituted identities' whereby active participation in the creation of lived experiences was seen as re-forming the once ruptured identity. Similarly, there is a sense in which within this study, participants' many varied diabetes and general health related activities (here articulated as 'resistance' to constructions of passivity) can also be regarded as a form of repair to identities. This sense of somehow identifying a disjuncture in one's life – the biography – and then doing something about it involved two dimensions. One is related to the doing, while the other is related to the narrative account where certain constructions of self can be accomplished. Although this work does not concentrate wholly on this narrative account construction, it is relevant because as Blaxter (2004) argues narratives allow people to rearrange their experiences, and organise and present their actions, to articulate their place in the world.

Having discussed how Bury's notion of biographical disruption and Williams central idea of narrative reconstitution can be applied to facets of the experiences of these participants, it may be possible to proceed a step further, or at least make an additional contribution. Given there is a range of physical, social and environmental factors
which affect the cross connection between identity and health (Kelleher and Leavy 2006), there may also be a possibility to keep this theoretical momentum. The physicality of an illness such as type 2 diabetes, its symptoms as well as implications, combined with socially and culturally located issues affecting how diabetes is managed, point to a form of bio-narrative reconstitution formed in and through the health and illness narratives of people in this study. It is possible to suggest that through the invoking of various types of narrative, or life story, people were asserting the sense of biological physicality and social and cultural placement of their lives. Through talking about their experience – and always located in a temporal and spatial sense – people were bio-narratively reconstituting elements of their lives.

The role played by biography within this study is central to the methodological and substantive area in which it sits, since it is only through people's biographies that empirical findings have been asserted. The stories told by people were in a sense both a retelling of elements of their lives, and a continuous reformation of a notion of social, ethnic and cultural identity. As Riessman (2001) has argued, narratives are not only personal tellings, but public issues, pointing to social issues that can be addressed. In this sense, and invoking Mills's (1959) argument regarding biography, history and society, there is a strong notion of the dialectical relationship between agency and structure – that through the reflective appreciation of biographical work, it is possible to address both social structure and the acts within it. Personal experiences of the body in states of illness awareness are juxtaposed with public experiences of, for example diabetes diagnosis, care, and systems of treatment. Added to this are of course the social and cultural milieu within which people act, such as the time period people arrived in this country, experiencing adversity, the issues around finding work, and the coping strategies employed for this problems, which permeated their life experiences.

Contextualising the experience of diabetes among the people in this study by looking to biographical features helps to extend the diabetes experience arena (and health and illness sociology in general) to insights about how a person's own understanding of
their 'troubles' can in turn be related to social analysis. This as Riessman (2001) argues can in turn be directed to an analysis of larger social complexities or systems. In this study for example we can see how a person might go through what might be regarded as routine process of diagnosis, go onto manage their diet and lifestyle, and perhaps use different remedy systems. Exploring people's own notions of what they do and how they come to think of these actions gives us a clue about the symbolic significance of what their actions hold. In this study, what I articulate as 'resistance' is a set of actions which constitute culture as dynamic and malleable, and perform complex functions for people to negotiate their landscapes. Their use of various resources then can only be gleaned via biographies – their histories. As Plummer (1995) has emphasised, stories bond together people's histories, identity and politics.

7.4 Theoretical frameworks

The underlying approach used in this study has been explicitly a grounded theory framework, which has allowed the integration of emergent findings and tentative theories, so that a constant comparison and testing could take place during data generation. This however does not exclude the use of theory at early stages – indeed during the early processes of thinking through questions for interviews, examining literature and studies, and establishing research directions, there were a number of ideas which have remained powerful pointers in terms of theoretical direction, as well as being 'tests' for usefulness. Kelleher's use of symbolic interactionist ideas (1996), as well as his application of Schutz's notion of *structures of relevance* (1966, 1971) have found useful purchase within this study. Of course as this study utilised grounded theory approach which facilitates emergent findings and theory, these ideas were not overtly employed though they provided a powerful interconnection between the diabetes experience and ideas of ethnicity, culture and identity. What this study does is take this set of conceptual (and empirically grounded) tools, and connects them to the emergent findings.
It is possible to ascertain how the phenomenological idea of 'structures of relevance' informs the current work. Kelleher’s use of this idea stems from his defence of using the term ‘culture’ within research into health and ethnicity, so its usage serves as a specific conceptual tool within diabetes and ethnicity research, but also within the general arena of ethnicity, identity, culture, health.

Kelleher argues that while class differences are major determinants of peoples’ lives, culture and ethnicity are still important because they are “self-maintained” (1996: 77) to some extent, and that people do not simply follow in a straightforward manner a set of cultural rules. Rather they actively construct their ethnicity by “trying to reconcile and integrate the sometimes conflicting structures of relevance in their lives...This is a symbolic interactionist perspective...” (1996: 77). These structures as detailed by Kelleher are aspects of the social world which affect and impact upon how social action is carried out. In Kelleher’s study of diabetes of Bangladeshi groups in London, there were a number of competing and conflicting ideas such as managing the symptoms of diabetes, deciding on dietary changes, managing medication, and taking exercise. These requirements have to compete with other priorities in people’s lives which form the everyday content and substance of social lives and are common to the experience of type 2 diabetes. Using the notion of structures of relevance, it is possible to locate the management of diabetes within the wider lived, social and cultural world that people occupy, so that ethnicity – that sense of ethnic identity which is both self-maintained and reactive to wider structures – becomes a structure of relevance. Kelleher’s point is that in health research while it is not sufficient to simply locate people, or groups of people within certain ethnic groups to produce generalised understanding, it is crucial that there is an acknowledgment of the two way process of identity formation. This in essence is attempting to handle the original sociological question of agency and structure. With reference to ethnicity it is important that we have an idea of how people see themselves as well as examine constructions of people as members of political entities. In Kelleher’s (1996) work, ethnicity is seen not as a one-way, top-down process of allocating labels, but as a
structure of relevance, a meaning-producing experience, as well as an engagement point to the wider social and political context of people’s existence.

The relevance this has for the current study is that notions of Hindu Gujarati identity, how it might be maintained and implemented using various methods elucidated via diabetes accounts, can also be regarded as structures of relevance. Given the myriad competing requirements which are faced by people who have diabetes, the findings in this study indicate that there is a lived, social and cultural context within which diabetes is embedded, and ethnic and cultural identity is part of this network of relations. The way in which diagnoses of diabetes were sometimes ‘double-checked’ using overseas contacts and newspaper articles in the Gujarati press sent from India are an example of this. Similarly, employing knowledge of herbal and traditional medicine for both specific diabetes and more general health maintenance can also be seen as a form of utilising culturally framed knowledge as a structure of relevance. If we take this term ‘knowledge’ and recognise, as Ferreira et al (2006) do that it can be a major modality of culture we can gain an insight into how people experience the world and act within and upon it.

‘Knowledge’ within Ferreira et al’s anthropological framework is both the starting point and the intervention method in community empowerment for indigenous people with diabetes. The use of herbal remedies, as was demonstrated by many of the participants in the interviews in some detail, is a cultural and local knowledge, an expertise which is adhered to and relied upon, not simply in terms of its immediate value, but also in terms of where that knowledge came from. As one of the participants explained to me, ‘we’re from India, we used to use this there, so we know about it’, demonstrating that in this action of utilising both her prescribed medication and using herbal remedies, she is framing her cultural and ethnic identity. This is done through her story of community voluntary work, connections to relatives overseas and her adverse experiences in the UK during the early settlement periods as well as her social identity being steeped in a history of survival. Her use of traditional, herbal and established vegetable remedies for diabetes, such as karela in the form of curry
demonstrates the point made by Garro and Lang that “Food and food pathways constitute complex codes for social relations and symbols of cultural identity and change” (1993: 322). While this study did not specifically focus on the anthropological notion of ‘food pathways’ it is not a huge conceptual leap to discern the symbolic universe being enacted here. This connection between the diet and nutritional facets of the diabetes experience and the use of both medication and herbal / traditional remedies can also be reflected in the notion of syncrecy. Nagel’s interactionist notion of symbolic ethnicity highlights how “ethnic identity then is the result of a dialectical process involving internal and external opinions and processes...” (1994:154) connecting the current study to Reed’s (2003) work on syncrecy and dialectical models.

In the dialectical approach, there is the positioning of two forces, interacting in a process under constant change and tension. This dialectical process can be used to investigate how cultural and ethnic identities can often be in tension, and with reference to health and illness states and interactions, insights are possible without framing pathology or abnormalising any one entity in the process. Reed (2003) in her work on British Asian mothers and health choices employs the notion of syncrecy to reflect the mixing and matching of health remedies, certainly something which has resonance within this study. Although as Reed observes, syncrecy as a concept in health studies has been in use for some time now (see Fitzpatrick 1984), she also alerts us to the fact that it has not been used extensively in ethnicity and identity - which is an innovation demonstrated in her work.

The problem however with using the notion of syncrecy is the common problem with many of the concepts discussed here – they can be reified and rendered static, and used to denote a state, rather than a process – something which Reed (2003) argues can lead to the connotation there is a ‘pure’ state that can be compared with the ‘syncretic’ state. Given the history of power relations within the field of symbolic and political markers of difference, it is easily discernable that a visible or identifiable minority would not take the role of the ‘pure’ in identity states. This is a risk that can
be evident within this study - that those syncretic health choices that participants made, for example deciding to use different medicine systems, acquiring advice from another source or complimenting their daily routine by watching yoga sessions broadcast from India could somehow be fixed in a state, and be the result of something that minority cultures might do to express their ‘cultural ways’.

In addition as Reed argues there is the risk of setting up the interactions as somehow “between two cultures” (2003: 14). This risk is avoided by situating the syncrecy within a dialectical framework to “explore crossovers and tensions between categories of difference...(which) allows the potential for tensions...at particular times and contexts...syncrecy is seen as fluid and poly-vocal” (2003:14). This was illustrated by Kanti in her life narrative, detailing how within her upbringing in India, she and her family had lived within multi-cultural faith and linguistic environments, and this notion of living with a multi-faceted society had been transposed to the UK. As she stated, “we became multi”. This ‘becoming multi’ was a feature of her overall strategy to living life, and dealing with health and illness states. It was also a mode of operation which fit comfortably with her role in the community as a cultural organiser and spokesperson, demonstrating perhaps Blaxter’s (2004) notion of identity “as a grid through which health and illness are perceived and given meaning...and in turn health and illness construct(ing) identity...” (2004: 170).

This dialectical mode of operation is also used in the current study to inform interpretations and explore expressions of health, illness and diabetes management, in the context of everyday life – in the immediate present and in the past. For example, when one of the participants (Harish) talked about his being able to manage his diabetes very well, almost to the extent of it being a normal, everyday occurrence given his long experience with it, he also talked about his experiences in settling in the UK in the early 1960s, problems finding work, experiences of prejudice and racism. These features of his experience – and it should be noted the experiences were shared with his wife – were influential in how he felt he could deal with general health management as well as specific diabetes management, but also how he talked
about these experiences. His migration history, trajectory, status, social and professional connections in the past combined with the adverse experiences in the UK as a migrant were part of his everyday strategy in managing social and cultural life. This was also juxtaposed with both his and his wife’s positive relationships with local people in their area, which were facilitated by a shared ageing characteristic, but importantly also by the shared experience of adversity. As Harish explained, the generation who lived through the world war had knowledge and experience of hardship, and this he felt was a point of connection between them.

7.5 ‘Resistance’

Interconnections and tensions are clearly laid out in the data, as people spoke about problems, issues, anxieties and obstacles, but also spoke about what might be described as ‘victory narratives’. Participants were expressing management mechanisms and coping strategies, enmeshed in a variety of lay health beliefs, which indicated a series of active negotiations occurring. These narratives are similar in form to what Bury (2001) has described as heroic sub forms of narrative, in his discussion of contingent, moral and core narrative forms. The common feature in almost every interview interaction in the study was that of active cultural negotiation of health and illness states, via expressions of cultural and ethnic identity manifested in local knowledge of herbal remedies, personal diet or medication regimes, and connections to other people as resources. While explanations would often be centred on the often cited ‘health discourse scripts’ regarding inappropriate food preparation and consumption, lack of exercise and a generalised notion of ‘genetics’, people would also balance the equation by expressions of ‘resistance’. Given that it is possible to identify the construction of a ‘South Asian diabetic risk’ through health discourse, the notion of resistance is of particular value here, and assists in articulating the social action in people’s narrative accounts.

People in this study openly talked about their lifestyles, routines, concerns and anxieties about their health, within the social context of their situation. They also
frequently talked about their perceptions of the causes of diabetes in their community. Many of the explanations were related to those ideas and notions which have been part of the prevailing health science discourse, such as the general idea of ‘genetics’, sedentary lifestyles, insufficient exercise and unhealthy dietary habits. These ideas have been generated in health science discourse, and at first sight it appears that respondents reiterated this. However given the chance to engage in more depth, they demonstrated many different forms of ‘resistance’ to these constructions. Their personal and family management activities, routines, conceptions of remedies and the constant processual nature of this syncretism revealed there was an active process of conceptualisation and help seeking, embedded within matrices of social action.

The findings from this study are organised around three core areas – principally the diagnosis, diet and food routines, the use of complementary, traditional and herbal remedies, and the notion of cultural identity and biography. These findings demonstrate that firstly the experience of diabetes is far more complex in a culturally and socially situated way than is taken for granted. Secondly using various mechanisms within their cultural and social repertoire, people actively employ cultural negotiations in health and illness which can be seen as forms of resistance to the constructions of South Asians prevalent in health discourse.

This juxtaposition between reiterating the ‘risks’ related to South Asian diabetes, and the gradual excavation of deeper levels of expression – the ‘resistance’ - may indicate parallels with Cornwell’s distinction between ‘public’ and ‘private’ accounts (1984), corresponding with “abstract terms” and “concrete experiences” (Nettleton 2006: 44). It is plausible that participants were performing a form of ‘health script’ either because of familiarity and exposure to health promotion discourses, or perhaps as result of my presence as a researcher who might represent official establishment or authority. However as Radley and Billig (1996) argue, it is not a simple case of people providing one type of account in one situation, then producing a different account in another. Rather, even within what we might call ‘private’ accounts, there is a process of “rhetorical accomplishing” - so that a participant will produce an impression of a
‘public’ nature such that a moral accomplishment takes place. In this study, participants often talked about experiencing severe physical, bodily and emotional obstacles in their everyday lives. These could be heard as ‘private’ accounts, which may not be demonstrated anywhere outside of this situation. However, even within these ‘private’ accounts there is a moral accomplishment taking place, enacted in what might be called a ‘victory’ narrative which is an account of overcoming and winning against all odds. In Radley and Billig’s (1996) terms, they are private accounts containing public dimensions. The ‘truth’ of the reasons behind their talk is not the focus here, what is more important is the elaboration of these narratives as resistances working through cultural negotiations.

By using ‘structures of relevance’ as elaborated by Kelleher (1994, 1996), there was a sense in which people were constructing the fluid and dynamic notions of their ethnic identities in the accounts and in the observed activities – a symbolic ethnicity (Nagel 1994). I have argued that it is via these proccessual cultural negotiations, that respondents have resisted the construction of the risk laden ‘South Asian’ identities as generated by health science discourse.

This demonstrable resistance is generated through social and body politics. In Foucauldian terms, the body is constructed through discourses and practices (Lupton 1997), rendered docile by the specialised and professional gaze of the medical encounter and establishment. Disciplinary power exercises its authority over the body, its appearance and state, by regulation and objectification, served through observation, measurement and comparison (Lupton 1997). However, it is also through discursive practices and the production of knowledge that a type of body (a representation) may be generated and maintained. I argue it is possible that various forms of knowledge production have done precisely that – created a form of ‘risky South Asian body’, and the study has performed a function of highlighting the forms of possible resistance to these constructions.
The people in this study were employing resistance to these overarching discourses pertaining to their bodies and their lives. This idea of resistance is given some treatment by Foucault (1988) in the context of the production and effects of power. While the 'docile' body (Armstrong 1987) features heavily in Foucault's' work, Lupton (1997) points out the contrast with his treatment of resistance. This later 'ontology of experience' work indicates that where there is the production and application of power, there will be a resistance to and through it. Shilling (1991) re-envisages how this resistance might be manifested by arguing for a phenomenology of the body, in order to investigate how people respond to external discourses, and what role mediating factors such as gender, ethnicity and age might play. The bringing alive of the previously conceptualised docile body (Shilling 1991) not only signals the re-rendering of the biological-social duality, but also the relationship between categories of difference imposed by external defining structures, and notions of ethnic identity as created, maintained and negotiated by people themselves via cultural negotiations.

### 7.6 Cultural negotiations

As already evidenced, much of the discussion surrounding type 2 diabetes focuses on adherence to medicine, advice related to diet, nutrition, exercise, and glucose monitoring. However, there is a place in the type 2 research arena for more in-depth work to be done on those aspects which involve reconstructive social processes, through narration and biography. The process of re-negotiating identity needs to be placed in the context of categories of difference. For example, how does an elderly South Asian woman, who has been diagnosed with type 2 diabetes, suffering from symptoms of fatigue and pain, experiencing isolation, and language barriers, deal with her diabetes and negotiate her social landscape? This may be placed within the context of socio-cultural milieu, so that factors such as her migration history, networks with friends and family in India which may facilitate her contacts with complementary medicine and social, cultural and religious connections in the UK, produce a more rounded and richer picture. This more 'nuanced picture' of
‘constructions of ethnicity’ as Smaje (1996: 165) argues for is possible through qualitative and ethnographic methods, focusing not on simplistic dualities, but on revealing various intersections of social and economic experiences.

Participants spoke about experiences of racism, struggle, building communities, families, but also sharing interactions with people in their localities – British South Asian and British White. They demonstrated that the things they actually did to cope with the illness were varied, numerous, and consistent with their (stable and fluid) ideas of who they were in the context of their past and the present. This was a constantly negotiated order utilised effectively to actively assess their health and illness states – specifically their diabetes. Sometimes they would use traditional medicines, combined with allopathic medicine; sometimes they would reject the traditional because there was no objective evidence about its efficacy. Eade (1997) has argued that the use of combinations of remedies is reflective of the process of cultural constructions. This syncrecy is often demonstrated in the ‘dialectic of the local and the global’ (Giddens 1991:22), touched upon by Kelleher (1996), and elaborated further by Reed (2002) who uses the dialectic model as a framework to explore poly-vocality and expression of difference through syncrecy of health choices. Reed (2002) uses processual syncrecy, as opposed to a static state position, to get around the assumptions of hierarchy connected to dominant medical paradigms compared to traditional remedies and knowledge. This approach facilitates the situating of difference in a historical and biographical context.

This study draws upon these findings and further encourages health research to employ this multi-faceted appreciation of culture and ethnicity. The dialectical relationship was manifested in this study via a number of routes: the local and global relationship in terms of healing products (Reed 2002) and intellectual products via news media; the relations within and outside the country utilised to make sense of identity and the management of the illness; the temporally situated accounts and personal biographies of the respondents which were located in histories and experiences of Africa and India and in the immediate and current communities of
which they were a part; and the relationship between myself and the respondents, through the negotiated form of ‘cultural validations’. As the data indicates, the dialectic of the local and global is active in many different forms in people’s lives as they both make sense of the illness in their lives, and activate notions of identity through manifest, concrete and practical methods of health management. Some participants while might have been aware of a general idea of herbal remedies, especially those who were not yet of senior ages, would also acquire both information and products from contacts outside the UK, usually located in historically connected diasporic places, such as Africa, India and South Africa. This dialectic however was not limited to simple geographical dualisms, but also more complex dialectical relationships in terms of accessing information about exercise, an example being the use of yoga broadcasts from India in conjunction with exercise prescribed by doctors.

7.7 Resistance through embodied practices

There is empirical and theoretical justification in stating that the processes of cultural negotiations in health and illness, articulated through what has been defined here as ‘resistance’ to constructions of a particular risk, are activated through embodied practices. As Williams (1995) and Turner (1992) have emphasised there is a fundamental need for sociology itself to be an embodied project. It is via this embodiment that the body is maintained in the equation as one of the sites of resistance and cultural negotiation. These resistances take place, using cultural practices located in systems of knowledge, which in totality make up an experiential universe of both practice and meaning. We can see this happening when herbal knowledge is integrated into forms which are more easily accessible (for example a grandmother making herbal health shakes for her grandchildren). This is part of people’s embodied practice and culturally negotiated processes where they are integrating syncretic forms of knowledge of the body and healing systems. They are also combining forms of identity maintenance – some related to being a South Asian in the UK, others to do with religion and faith frameworks, and yet others to do with their identity as a family, trying their best to cope with health and illness. Participants
present active social and personal selves in relation to their illness and the social contexts they find themselves within. The problems people faced in language barriers, experiences of racism, the dominance of the medical model of treatment of diabetes and the availability of information (amongst others) were all issues which were faced using 'local techniques and strategies of power' (Lupton 1997: 103). It is through these forms of resistance that people were activating dynamic notions of cultural and ethnic identity. In a sense they constituted culture in all its fluidity, using whatever resources they had – including their shifting identities. Hence, they were ‘making culture’ as much as responding to given notions of it (Lambert and Sevak 1996).

By using this idea of ‘resistance’ it is possible to render health and illness as the subject of both political and individual experiences. It is this agency which allows people to configure their own perceptions of their identity within society, and actively engage in decisions about their health and illness states. The appeal of this approach lies in the acknowledgement of macro processes that affect social actors’ movements, combined with the liberty provided by active and negotiated decision making. People in this study utilised many resources around them, including their memberships of different groups, their involvement in local and global dialectics, as manifested in remedies and nutritional ideas, and their conceptualisations of ‘ethnic’ and cultural identity framed by their migration histories, and local relationships. This allows for the complex interplay between agency and structure, providing a framework that observes power and structural inequalities, as well as individual and group choices, and the active summoning of cultural resources to manage a variety of experiences including type 2 diabetes. As Kelly and Millward emphasise, “...the agency structure question remains sociologically under-analysed in the literature on the experience of illness and the construction of identities therein” (2004: 3). It is hoped this study furthers this project conceptually, methodologically and empirically.

Thus far in this study there has been a narrative thread which traces an ontological and epistemological story about the experience of diabetes amongst a group of Gujarati type 2 diabetics. This narrative thread however also involves the demarcation of the
story of ‘difference’, how symbolic markers of difference and sameness are maintained, negotiated and played out in the field of social action, especially with reference to health and illness. The narrative however also runs to the methodological underpinnings of the study, given the earlier discussions regarding the process of ‘cultural validations’, and involves the process of framing identity. In a sense this study is concerned with this question of identity most of all, and how cultural and ethnic identity might be played out and manifested against a fluid social backdrop. To this end, a number of theoretical perspectives have been mobilised here, including as seen above, symbolic interactionism to situate structures of relevance and symbolic ethnicity, and Foucault’s work to help articulate the notion of ‘resistance’.

7.8 Theoretical developments

Extending the need to contextualise cultural difference in society, Bourdieu’s development of the ‘habitus’ (1977) is an idea that allows ethnic identity to be regarded as historical and social codes, and are part of a series of strategies that an individual will use in varied forms to negotiate social situations. Several theorists (Spencer 2006; Smaje 1996) have called upon Bourdieu’s theoretical framework, providing a platform for investigating how ethnic identity connects to our ideas of society, suggesting that most other theories of ethnicity and difference favour either the individual or society, thereby tilting the balance of social action one way or another. Smaje (1996) takes exception to the ongoing and persistent inadequacy of theoretical approaches in tackling the structure-agency issue, and opts for Bourdieu’s idea of the habitus as a way forward.

The point of connection with this study and its placement therein comes from the viewpoint that the ‘habitus’ as a set of dispositions, ideas and ways of being which are generated and produced through lived experience and practices, structure people’s orientations to the world. Rather than limiting and determining social action, they enable social interaction to take place. Thus, this theory of practice is crucially concerned with the habitual representations in social action - those bodies of
knowledge, skills, ideas and precepts which people use all the time. Interactions between an individual and the established social order occurs via the habitus schema. This dialectical process provides a way of rendering a picture of ethnicity, and allowing us to see how the experiences of the participants are mediated by this. Thus, Bourdieu (1977) demonstrates how people can manipulate social categories but within the framework of the logic of the habitus, so that a self-identity is constantly in a relationship – often of tension – with the identity imposed by others. As Spencer (2006) postulates, ethnicity can be seen within this light as a stock of strategies that can be implemented depending on context. Again this connects to the earlier discussion of Schutz’s (1966) idea of structures of relevance as shared frameworks within which people employ personal and individual choices.

The point for this study and the findings within it is that as Spencer (2006) states, ethnic expression is potentially reflected in lived experiences and habitual practices, which in turn produce the codes and meanings through which people manifest social action. So while there will be differences between individual habitus which can be found in how people construct their own flexible and dynamic choices for remedies for diabetes for example, they are also constrained by the ways and means of particular groups, governed by norms and traditions. This then brings the discussion back to the idea of ‘resistance’ via a dialectical model, so that the (risk-laden) identities of South Asian diabetics that may be sophisticatedly being constructed as part of wider health discourses are ‘resisted’ by people actually involved in ‘cultural negotiations’.

Using Bourdieu’s ideas of the habitus means that potentially we are not entirely restricted by the legacies of what may or not be seen as ethnicity, class or gender. Rather we can see how people use the various practical and symbolic resources around them based on the dialectical machinery of structure and agency – to achieve and produce social and cultural accomplishments. The framing of health and illness experiences using the idea of habitus has also been entered into by Williams (1995), while Spencer (2006) has as described above discussed its merits for ethnicity.
Taking impetus from Bourdieu, Williams (1995) relates the dual nature of peoples actions, that although there is a taken for granted quality to social practices, there is also a practical purpose and intentionality involved, when locating people's practices in their own experiences of reality. This means that health related behaviour “is itself a routinised feature of everyday life...woven into its very fabric”, (1995: 583). We can therefore make a direct theoretical and empirical link to notions of identity and ethnicity by connecting this interwoven nature of health with the demonstrable notion of identity, manifested within such health related behaviours. An example from the findings in this study is the use of traditional, complementary and herbal remedies for diabetes and general health. Although there may be a routine, unconscious sense in which practices (which are part of a cultural system of knowledge) take place, there is also an active, fluid re-forming of practices which enables social action to occur, exemplified by Naresh, who receives newspaper information regarding diabetes from a relative in India, and uses this to confirm details of his condition.

Within this study we can underline these habitus framed experiences with the notion of 'resistance', as articulated by people talking about their socially and culturally embedded experiences of diabetes. It is through the symbolic interactionist viewpoint of ethnicity as a structure of relevance in health and illness that we can connect their bio-narratives to the various ways in which they accomplish and achieve dynamic and flexible notions of culture and ethnicity.

Although Smaje (1995) used the notion of the habitus to discuss health and ethnicity, unfortunately his arguments do not extend to the other elements of Bourdieu’s (1977) ideas such as ‘field’ and ‘capital’, both of which are important for a discussion of the habitus. ‘Field’ is the term given to a system of social positions, in which the positions occupied are determined and influenced by power relations. It is through these relations that access to various kinds of resources can be created - more commonly known in Bourdieu’s work as forms of ‘capital’ – cultural, social, economic and symbolic (Jenkins 1992). It is through the ‘field’ that forms of capital are effected and the habitus works within the context of the field. What emerges in relation to the story
of diabetes, identity, culture and health amongst Hindu Gujaratis is a picture of structure and agency, a dialectical rendering, such that in structural contexts, individuals can and do operate their own systems of knowledge, social connections, local and global linkages, and utilise their notions of identity to act out socially.

It is as Williams states, “a dynamic structure which is characterised by the struggles of agents concerned with maintaining or improving their position” (1995: 587). We can perhaps see parallels between this theoretical observation and the different ways in which people in this study operated forms of capital, from social and cultural in terms of linguistic expertise and knowledge about herbal and traditional medicines, to symbolic capital, whereby people would offer ‘versions’ of their honourable and prestigious self in relation to health promoting activities.

It is possible to place the framework of the study as a possible contribution to the structure agency issue in relation to health and ethnicity, while at the same time emphasising, as is the constant theme in this study, the notion of ‘resistance’. As Williams observed potential and fruitful explanations in the area of health may lie in the exploration of “reflexivity and cultural resistance” (1995: 601), and offers the intellectual and empirical challenge of recognising the dialectical inter-connection of “freedom and constraint in daily life” (1995: 601). This is where the current study finds itself at a theoretical nexus, incorporating ideas from interactionism, dialectical syncretism, Foucault’s notions of resistance to power, and potentially developing Bourdieu’s framework of the habitus.

The aim here of course in this multi-pronged approach is to tell the story of diabetes experiences, in a social and cultural context, so that the interaction of individual agency and wider structures is recognised. In relation to this, Bourdieu’s work has been criticised for the underestimation of fluidity of lifestyles, and as Williams (1995) observes, lifestyles are not often characterised by neat forms of stability and unity, but rather are more unstable and multi-faceted. Additionally, the concept of habitus has been critiqued for its sense of mystery, as it is often described in terms of its operation
beyond the agency of the actor — meaning that agency is taken away from the individual, resulting in determinism, loss of control and knowledge (Jenkins 1992). Bourdieu (1977) has in the past argued that researchers eliciting accounts from respondents are carrying out a futile task, since ‘official accounts’ are simply what people think they ‘ought’ to say, rather than what they either want to say, or talk pointing to actuality (Bourdieu 1977). This is due, amongst a number of reason, to the relationship between participant and research — Williams calls this an ‘outsider-oriented-discourse’ (1995:584), whereby due to an assumed unfamiliarity, these accounts are simply general accounts, where information is non-specific and non-particular. This charge can be directly refuted in this study, firstly by the now long established validity and reliability of these interactions through qualitative research (Denzin and Lincoln 2005; Seale and Silverman 1997; Silverman 1993; Mason 2002), and secondly through the process of ‘cultural validations’, proposed and utilised here. It is through this processual interaction of biographical linkages and interconnections of identities that accounts in this study could pass from the general to the specific and from public to private. Given that the habitus has been defended as not just an abstract concept but exists through concrete practices and interactions, it is only fitting that a concrete, situated methodological practice is used to enter people’s cultural and symbolic worlds. By being explicit about the researcher identity interacting with the participant identities, acknowledging that during this process there are acceptances and rejections, it is possible to move to a situated and contextualised account.

Despite some of these issues, the theoretical stand still has strong purchase in this study, as rather than base the entire study on the totality of Bourdieu’s ideas; it feeds from it those strands which help to explain the story of diabetes in the participants’ cultural lives. Helman succinctly states “culture can be seen as an inherited ‘lens’, through which the individual perceives and understands the world…” (1986: 2). This study would add that, this lens is also a two-way, interactive lens, whereby people use and implement their frameworks of knowledge to see, interpret and act upon the world. These actions are also affected and contingent upon the incoming information and social action external to us. This has many parallels with the basis of symbolic
interactionism – that “meanings are social products, as creations that are formed in and through the defining activities of people as they interact” (Blumer 1969, cited in Collins 1985: 284). This seems to evoke the notions of identity that are raised and used within the accounts in this study, as people narrated their experiences of diabetes, life, struggle, migration and success. As Blaxter (2004) has argued the narrative can be seen as “a demonstration of the broader cultural world within which identity has a place” (2004: 170).

It may be plausible to question why this combination of concepts and theoretical frameworks has been employed in exploring the experiences of the participants. In a sense, the answer lies within the question – that to adequately and sufficiently examine health and illness experiences as they are located in terms of personal and social identity, there is a need to use tools which can generate explanations grounded in local, experiential frameworks. There is a real need to re-theorise health and ethnicity, not omitting or neglecting the large body of work that has gone before, but rather building upon it, so that simplistic, uni-dimensional and descriptive work within health is not perpetuated. In a sense this is a call for sociological analyses to re-question the complexity of social relations, and not yield to the temptation of stereotypes and caricatures of groups of people. The reasoning behind using this conceptual collection is as stated above to involve more sophisticated models of theory in exploring health and ethnicity. It also facilitates what observers in the field have been aiming for – a picture of the relationship between health, culture and ethnicity which fully acknowledges the elastic, malleable but also enduring nature of cultural identity. Ideas of who people are, were and may be in the future are formed, reformed and re-shaped according to frameworks of experience. The models used here allow the different conceptual and experiential layers to be sited in their contexts, which are subjective to both spatial and temporal dimensions.
7.9 Empowerment

There are parallels on an empirical, ontological and epistemological level with the current study on Hindu Gujarati people in this sample with the medical anthropological approaches discussed earlier in chapter 1. Empirically, the study has focused on people’s own life experience, their bio-narratives, and their active constructions and maintenance of health management via different and combined systems, using social and cultural webs of connections. Ontologically, there is complete concurrence between the stance of Ferreira and Lang (2006) and Scheper-Hughes (2006), and this study, in that notions of genetic risk, ‘cultural traits’ and ‘lifestyle’ are critiqued and contested as being the product of discourse formation. They are regarded as non-explanatory and constitute further evidence of pathologisation of minority groups. The picture painted by these anthropologists contributes to this work on South Asians because there are parallels on various levels, such as the construction of ‘risk’, the incipient use of cultural stereotypes in health interventions (Humphery 2006) and the acknowledgment of local, traditional knowledge. The process of ‘cultural validations’ employed in this study, which provided not just access to people and places but also facilitated the explicit interconnectedness of identities in the research owes a debt to anthropology in its requirement of depth situating. Medical anthropologists have equally and more so used situated accounts and observed the powerful telling of diabetes narratives to tell the story of people and their diabetes as contextualised by social and political forces (Lang 2006; Omura 2006). Perhaps within this combination of medical anthropological community empowerment models (Ferreira and Lang 2006), the ‘sharing stories’ notion used by Greenhalgh et al (2005), the critical role of interconnectedness of identities in the research process and the theoretical formulations discussed earlier it is possible to situate this study in the wider body of work as an insight into socially and culturally contextualised diabetes experiences.

The notion of ‘empowerment’ brought about by the use of life-history methods in the 1980s and key to emancipatory tools in welfare practice (Chamberlayne et al 2000)
carried a particular weight within this study. As shown above, in-depth biographical work serves to locate people as historically formed, but also as immediate and current social actors. As Erel (2007) has demonstrated in work on migrant women, biographical methods and the analysis of storytelling have the potential for transforming what Foucault (1980) would regard as subjugated knowledges. While Ferreira and Lang (2006) do not explicitly discuss Foucauldian approaches, there are interesting connections here, given the importance of life stories, and the use of biographies in this study. As dominant paradigms create and maintain structural positions within which actors operate, the transformative potential of life stories, as Erel (2007) articulates, is found in the way people communicate their counterstructures – resistances – to immigration control. Here we can discern parallels to our biographically informed social action, articulated as forms of resistance to the dominant construction of South Asian diabetic risks. Biographical life stories of the Gujarati people here and the articulation of their experiences, embedded in what people do to deal with their condition thus run counter and “challenge the positions ascribed them structurally and discursively” (Erel 2007: 9.3).

7.10 Cultural reproduction

Within the story of diabetes experience in this group there is also the notion of cultural reproduction. By actively using herbal remedies, recalling oral and practical traditions, by linking to relations and others in other countries where there is some connection (India, Africa), and by providing these forms of healing and health maintenance for subsequent generations, people are involved in the act of cultural reproduction and maintenance. It is through the embodied practices of managing diabetes using the resources around them that people can and do seem to maintain the sense of who they are and why they do the things they do. The resistance to constructions of South Asian people as being somehow genetically or culturally inclined to suffer seem to be evident in the social and cultural actions of people. What they do, what they say they do and the ways in which they conceptualise, explain, and talk about their experiences – both in history and in the present – tells us that the
picture of diabetes, and health and illness generally in this group is far more complex than much discourse indicates. What exists here is empirical evidence of a situated, qualitative nature that reveals there are many varied elements of the individual experience and narrative which can be utilised, with them in partnership, to create empowered states of health and illness management.

The current study provides both an ontological and epistemological statement, which takes difference as a fluid and negotiated order. It is regarded as both a construction and an effect of power relations, but also a distinctly utilised category of social action. The core areas of this study are connected by this notion of difference, but also the key idea of resistance using cultural negotiations. An empowerment model which employs methodological reflexivity, cultural validation processes and a critical notion of difference might be able to locate the importance of experiential knowledge bases in diabetes as a culturally and socially situated illness.

The following chapter will establish some conclusions which can be drawn from this study, and move onto a critical evaluation of the work, focusing on areas which can be developed further in terms of practical, service provision and theoretical arenas.
CHAPTER 8

CONCLUSION AND CRITICAL EVALUATION

8.1 Conclusion

This thesis has explored the research arena within which this study sits, the theoretical and methodological basis used to generate the data and tentative explanations for the social phenomena, and finally discussed what these findings mean and where they sit within theoretical approaches in this arena.

The goal of this research has been to explore the ways in which a particular group of people think of diabetes, how it affects their daily lives, and the kinds of things they do to manage it. This however is not a cultural reductionism — rather the aim is to examine what symbolic and practical significance can be gleaned from what people do and the way they talk about their experiences. The interview data shows that when looked at in some depth, and contextualised by biographical and life history, what people do in their social action is dynamic, flexible, adaptive and constitutes agency in negotiating health and illness states. These active agencies are demonstrated within social, political, cultural and historical milieu so that within people’s stories we have an indication that there is a structure and agency dialectic in operation.

The stories and experiences people have talked about in this study were also empirically juxtaposed to the way in which health science discourse has constructed their actions, inactions and responses to health and illness. These constructions have in the past - and in many cases continue to - employ stereotypes of ethnicity, culture, and markers of difference. Groups characterised by heterogeneity of language, culture and faith are often lumped together for the purposes of ‘health’. The impact of this is not simply conceptual or academic - there are concrete effects on generations of people, driven by ideological and political processes. This study has aimed to highlight these constructions by identifying the main types of explanation and
‘education’ provided by these discursive arenas: lifestyle, genetics and culture. By exploring people’s accounts of their lives, and how diabetes sits within a bigger ‘life’ scheme of lived experiences it is possible to discern how the social action demonstrated can be articulated as ‘resistance’ to discursive, racialised constructions of passivity. Through the situated, ‘culturally validated’ qualitative methodology used, people’s stories are seen as resistant to the dominant, discursive arenas which maintain stereotypes of ‘ethnic’ health. Far from being passive, the participants utilised a variety of social, cultural, ethnic, religious and biographical resources around them – as a matter of routine and everyday occurrence. It is within these manifestations that culture in its dynamic and flexible capability is shown as a tool kit to manage, survive and live in a changing landscape. The experiences, histories, biographies and notions of identity which people had were constantly in use in the routine management of diabetes. As shown earlier, a number of themes emerged: the double checking of the diagnosis via connections overseas using printed media and social networks; the syncretic use of allopathic, traditional and herbal remedies mediated by both a historical, familial knowledge of remedies, but also a current and immediate engagement with the system via local, social connections and the mapping of experiences in Africa and India to experiences of migrating to this country – again temporally mediated within biographical contexts, but utilised to deal with social landscapes. These elements of ‘knowledges’ (Ferreira and Lang 2006) and what others have called ‘subjugated knowledges’ (Erel 2007) form the ‘resistance’ which empowers people to actively negotiate their health and illness states. This sociological project about type 2 diabetes experiences can also potentially provide some interesting and useful insights about the ways in which health, illness and forms of identity are inextricably linked through the dynamic negotiation of social and cultural landscapes. This thesis has aimed to provide empirical, methodological and theoretical in-roads to locating the Gujarati experience of diabetes in a wider socio-cultural and biographical context, thereby widening the lens with which the health and illness of these participants is viewed, theorised and acted upon.
8.2 Critical Evaluation

I will now turn to some critical evaluative ideas for the study. Some of this discussion has been touched upon in chapters 2 and 3, mainly because of the nature of the reflexive identity practice involved in the entire research process, but some I will attempt to discuss here. Firstly I will address the issue of any limitations that have been identified, and where possible how these issues might have been dealt with. Secondly, the topic of generalisability will be tackled, and the extent to which anything can be usefully said about phenomena outside of these cases. Finally the issue of recommendations and possibilities for future research will be addressed, with the aim that elements of this study can be used to provide another piece of the health and ethnicity jigsaw puzzle, empirically, methodologically and theoretically.

8.2.1 Language and Coding – the process of analysis in another language

One of the possible limitations of this study is the nature of the relationship between language and analysis of qualitative data. The language used in this research is not limited simply to the combinations of words employed for communication, but is, as with all language a connection to a cultural arena. While my Gujarati is fluent and places both myself and the respondent at ease, there may have been some distancing created because the analysis is entirely in English. As Charmaz points out, “our codes arise from the languages, meanings and perspectives through which we learn about the empirical world, including those of our participants...” (2006: 47). This raised some questions about the ‘second-handedness’ of the codes that were generated, as even in vivo codes would of course be in English, rather than Gujarati. If we selectively choose the words to create codes relating to textual matter and then use these codes in further analysis to discern analytical threads, does this mean that the emergent theory which is intimately related to the coding process is located further and further at a distance? This question has been raised a number of times, and cannot be answered simply by stating one’s fluency in the language alone. Rather, as Charmaz (2006) explains the process of going through the transcripts over and again.
is itself an interaction with the participants, the contexts of the interview situation, the interactions surrounding the event, and our subsequent thought processes since. This interaction, allied with more than a passing skill in the language and crucially a knowledge and experience of the ‘cultural frames’ of the participants, is how this risk of second-handedness can be overcome. In addition, regarding some data as somehow ‘pure’ or more authentic and other data to be more ‘distanced’ for a variety of reasons constructs a false ontological and epistemological polarity. Given that all data generated in interactions are subject to some interpretation, the notion of ‘second-handedness’ requires careful consideration. In this study the analytical process was helped by knowledge and experience of aspects of the cultural worlds of participants, from linguistic nuances, to common knowledge of various foods and herbs, through to familiarity with people’s names and villages in India, Africa and England. In this sense, processes of cultural validations, alongside vigilance against assumptions about commonalities is what brings about an emergent theory which is grounded in the data.

8.2.2 Time Frame

Another possibility of limitation within this study arises in the time frame of the research. Carrying out the fieldwork in separate sections or batches of interviews may mean that a certain ‘flow’ is either never reached, or interrupted, having consequences for the nature and quality of the data. Carrying out all the interviews in a small number of parts may allow for a greater continuity of process and analysis. However, given that generating a grounded theory involves a constant comparison and gradual build up of coding frames and then analytical categories, it is also possible that data generation over time does not harm the analytical process. When sections of the data are generated in chunks, as was the case here, it is possible that as codes are created and applied, patterns are discerned, and as is the case for grounded theory frameworks, memos can be produced which indicate where the data is either scant/vague or requiring further investigation in subsequent interviews. This was certainly the case in this study, where later interviews allowed for the pursuit and investigation of queries from the initial interviews. Doing the fieldwork work in
separate 'chunks' allowed for each 'chunk' to exist as a sole module of analysis — similar to a study on its own. By translating, transcribing, coding and analysing each 'chunk' it was possible to produce mini-recommendations for analysis so that each subsequent phase of data generation could take into account where focus was required. This applied as much to the interview technique as it did to the kinds of query and content of the interviews.

A concession within this limitation is that within hindsight, these 'chunks' of the study would be better placed if the time between them were kept to an optimal level — though even this is delineated by many constraints such as finance and logistics. In the final analysis the resulting robustness and validity of the study, the degree to which an emergent theory is grounded in people’s talk and the persuasiveness of the explanation is the ultimate assessment.

8.2.3 Sampling

In order to generate the sample, snowball and purposive sampling was used, and in many cases relied on personal recommendations from people (discussed in detail in chapter 2). This carried the risk of placing participants under pressure to take part and / or perform, thereby possibly lending an artificiality to the situation. ‘Gate-keepers’ who are contact points into various communities and groups are also occupying that position for a reason, perhaps related to power and status hierarchies. This means that if my role as a researcher is ‘validated’, then people within a given community may be under pressure to conform, collaborate and cooperate. However, this is perhaps negating people’s agency. As they demonstrated time and again potential and actual participants were far from passive co-operators, and in a sense this is what the process of ‘cultural validations’ points to. The researcher’s role and the participant’s role are constantly under respective scrutiny, earning both rejections and acceptances as the situations unfold. ‘Gate keepers’ were also in a position to wield their protective power – their positions of relative authority meant that they held peoples’ trust, and
this was to be taken very seriously – for example in helping to assess, scrutinise and validate an ‘outsider’, regardless of language, family connections, or religion.

The idea of cultural validations provides a conceptual basis from which a critical qualitative methodology can engage with ideas of identity – of all parties – and problematise the area, rather than stagnate in static polarisations. However there are limitations and pitfalls. Here, maybe cultural validations can lead to an over familiarity which may create a ‘false’ connection, a contrived ‘authenticity’, or may result in negative interactions e.g. mistaken identity. For this reason I did not carry out fieldwork work in community centres and temples close to the town where I grew up. Although I carried out two interviews there, there were I believe far too many connections, familiarities and histories for an in-depth study to be feasible. However, this is worked into the conceptual methodological model, because it is a process of cultural validations, not a state of validation, meaning it is contingent on social interactions influenced by biographies, histories and cultural components like language and behavioural nuance. This means that over-and-under familiarity are constructs allied to positivist notions of objectivity, a goal which is somewhat redundant here given the nature of subject interpretations working as the epistemological machinery.

Throughout the study, including the interviews, processing of data, analysis and write-up, I was aware that the very connections that I had made visible and subject of methodological advantage – the processes of cultural validations – could also be connections which could result in my expectations and perceptions being fulfilled by a participant eager to conform. Having these varied connections to people in this sample could potentially be a screen masking processes that were occurring in the fieldwork work and interviews. They could also have been shifting and diverting focus and attention away from categories that might be generated in the data, but were hidden due to these connections. In other words, there was always the possibility that (in the unfortunate phrasing) I had gone ‘native’ (Mason 2002). This is an unlikely scenario, for a number of reasons, embedded in the study design and the
epistemological underpinnings of the study. Firstly, the notion of being ‘native’ is laden with ideological baggage and its usage is therefore very problematic and can be critiqued on a socio-historical ideology basis. Secondly there is, as Coffey (1999) argues, more to the process than the ‘either-or status’. Rather as discussed in chapter 2 there is a possibility of real involvement in the setting, and a chance to critically engage with identity work, constituted by position, place and identity. This is also close to what Geertz termed “experience-near and experience-distant” concepts (1979: 227 cited in White 2001) and White’s (2001) call requiring a back and forth process between the two. This in a sense initiates a validity link to the body of the work in this study – the dialectical processes discussed earlier in the Methodology and the findings can also be found in how the data were generated and interpreted. The processes of cultural validations include tensions and tussles between forms of identity, and it is the critical identification and analysis of these processes that makes for validity and generalisability.

8.2.4 Generalisability

Although the findings from this study are part of a context specific, temporally located research process, there is also a need to place the meaning of the findings within a broader field of application. While the general discussion chapter has brought the thematic topics into the weave of both broader theoretical approaches and a more specific combination of theoretical frameworks, there is also the issue of generalising. This leads to the question can the findings presented here be usefully and validly applied anywhere else? Mason (2002) calls this the crisis of representation – how far is the interpretation of the data valid, and how could this be discerned? One option is to take a ‘standpoint’ – as for example feminist research often does whereby there is by virtue of membership a privileged status to the validity of the knowledge gained. The other is to acknowledge this privilege in others – respondent validation. This study does not take a standpoint view, as this sets up the researcher’s status as beyond question simply because of their supposed membership of a category or group. It also involves a construction of what it is to be a bone fide member of a group – the
assumption being that having a type of characteristic - sexuality, gender, ethnicity, or any number of arbitrary social or cultural roles can definitively locate oneself in the very heart of some given 'truth'. Respondent validation did not occur mainly because as Skeggs (1994) showed, there can be a problem with people outside a specific discipline fully understanding the interpretations. I would add here that there is the additional problem of being interested – the respondents in this study were not sociologists or anthropologists, but people living their social and cultural lives, who had agreed to spend time with me talking. They were explicitly not interested in a report of my findings, especially a sociological study written in discipline specific English.

Instead, I employ what Spencer (2001) has called strong reflexivity, whereby a responsibility for the arguments within the study is taken. I have described in some detail the kinds of interaction in each setting, the products of the interviews, and my interpretations, as well as how I arrived there using coding practices. This detail, allied with a rigorous analysis, explaining what people said and what these occurrences might symbolise for them and for the phenomena, may just be applied outside this context. As Riessman states, this is A story, not THE story, and as such is “a story that shines light on certain objects of identity and leaves others in the shadow” (2001: 81). One might argue that the methods and concepts in this study could be applied to a different setting, where different illuminations within the same arena might occur. As Bryman (1988) has argued it is not whether or not people within a community are 'typical' because it is not possible to define what typicality is. Rather it is more important to explore how for example people's diabetes management experiences can be related to a broader range of experiences. In this study this is certainly the case, as people’s specific experiences are related to symbolising broader experiences, and in addition these collections of broader experiences are then related to wider articulations. For example, an individual's coping style may be related to adverse migration and settlement experiences in the UK, but this in turn is related to the general racism and disadvantage that migrants often experienced. These are then related via diabetes management accounts to the
existence of ‘resistances’ to constructions of South Asian diabetes risk as constructed in health discourse. The individual experience is then related not just to broader phenomenon within the study, but also to wider socio-cultural and structural phenomena.

8.3 Recommendations – going forward

There is a possibility using the concepts and methods in this study to inform policy and practice in the health arena. Research into people’s everyday diabetes experience is now becoming popular, with a more vocal sociological lobby spearheading many co-collaborative projects (see for example Greenhalgh 2005; Lawton et al 2005; 2006). These amongst others are policy relevant and have direct community level impact value, especially focused on Black and Minority Ethnic communities and therefore play an invaluable role in qualitative, action research oriented health intervention. However work which is able to take this body of findings and practical implications and develop theoretical arguments concerning the broader issues of health, ethnicity and identity are difficult to involve in policy, distinctly because of the difficulty and complexity of the area. There is however place for this kind of work, and below are several recommendation for future work.

Research in the future could employ the explicit and critical reflections of researcher and researched identity – as termed here ‘cultural validations’. Although in many different arenas there is already a powerful expertise and discourse around this area (for example Shaw and Gould 2001; Bulmer and Solomos 2004), there is an ever growing need for the explicit exploration of this type of interaction within directly applied health research.

Future research based on elements of this work might also extend the sample size – not so that debates about quantitative validity or reliability are engaged - but simply to extend the scope of broader phenomenon, so that wider analytical nets are cast.
Potentially the categories and concepts in this study could be thoroughly tested and compared with newer emergent findings.

The extent and level of site ethnographies which took place could also be extended - in time as well as depth, so that a deeper, participant interaction takes place, and one where rather than a ‘snapshot’ of experience be taken (though this is somewhat ameliorated by the histories questioned in interviews), a more processual description is created. This in one sense is lacking in this research – that there are social, cultural, and political processes occurring within each of the sites I visited, and which will change over periods of time. As Charmaz succinctly states, “interviews never replicate experience, they render it. Stories in interviews serve new and different purposes than when originally experienced and first told” (2000: 288). This highlights both a limitation of the current study and a way forward for future research. Developments of this could include a number of interviews carried out over a period of time, taking into more detailed account the “ebb and flow of experience” (Charmaz 2000: 288). It would be analytically interesting to invest in this, and explore whether this might yield insights into health and illness experiences, as situated in local contexts.

8.4 Service Provision

While there are in existence many localised services which may informally cater for individual biographies and expertise in diabetes management, there is still a dearth of official government funded diabetes programmes which take a critical look at how people’s ethnicity, culture and identity impacts their experiences. As explored earlier, it is still possible to identify constructions of reified markers of difference, such that any changeable, adaptable and dynamic life management skills may be overlooked. Incorporating these allowances into community health programmes is expensive – in time and money, but the pay-off will be truly empowered collectivities, as found in the work of Ferreira and Lang (2006). The kinds of knowledge, expertise, training, and general experience which many people in this sample already were utilising was a
great boost to effective diabetes management. Dietary and nutritional requirements, exercise and physical activity, the use of complementary and herbal medicines, and the ways in which participants called on their ethnic and cultural identities as resources, either in a practical and concrete way or symbolically were in evidence. One of the recommendations therefore from this study is that current programmes which deal with diabetes – type 2 or 1 – need to make more critical use of this biographical and community expertise. Many of the sites of the study, mainly Hindu temples which also served as community centres and meeting points have a system of regular visits by health visitors, medical representatives and other people who talk to the groups. These are perhaps potentially very useful contact points for further development work in this vein. Involving groups within communities to engage and participate, using not only tried and tested empowerment health strategies but also the huge array of diverse skills that are extant would be an ideal way of collaboration for management of diabetes for life.

8.5 Theoretical possibilities

There are a number of theoretical threads which have been followed in this study, which have both lent a support basis for the study, and allowed insights to be gleaned. The symbolic interactionist take on social action, with its emphasis on the constructions of personal and social identity being a mirrored social and internal process have allowed the study to look at how constructions of health, illness and ethnicity can take place. This is evident in for example the way ethnic and cultural identity has been used as a tool in order to conceptualise and manage the condition. The data showed how in the lived, everyday experiences of people coping and managing with diabetes, an articulation of Foucault’s (1988) ‘resistance’ could be identified. Extending this using Bourdieu’s take on identity and structure, via the notion of habitus and forms of capital is a potentially useful avenue for exploration. Within this thesis, the linkage to Bourdieu’s work is theoretical, albeit useful, but in future research there may be some empirical and practical mileage in developing this line of thought, especially given the scarcity of health and ethnicity work which
makes use of these concepts. A further recommendation therefore is to take this as a starting point for further research which directly tackles different forms of capital, and develops the notion of habitus, within the health and ethnicity field. There are also many potential research avenues within the articulation of ‘resistance’ to health discourse constructions within people’s practices. A more dedicated and specific strand of this may yield interesting and useful results, contributing to the understanding of the health and identity relationship.
REFERENCES


Boeije, H. R. (2004) And then there were three: Self Presentational Styles and the Presence of the Partner as a Third Person in the Interview, *Field Methods*, 16, 1, 3-22.


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Pitchforth, E. and van Teijlingen, E. (2005) International public health research involving interpreters: a case study from Bangladesh, BMC Public Health, 5, 71


APPENDICES
APPENDIX A

UNIVERSITY OF SURREY ETHICS COMMITTEE FAVOURABLE ETHICAL OPINION CONFIRMATION
09 February 2005

Mr Harshad Keval
Department of Sociology
School of Human Sciences

Dear Mr Keval

Cultural Negotiations in Health and Illness: The Experience of South Asian Type 2 Diabetics (EC/2004/124/Sociol)

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 09 February 2005

The list of documents reviewed and approved by the Committee is as follows:-

Document Type: Application
Version: 1
Dated: 10/12/04
Received: 14/12/04

Document Type: Research Protocol
Version: 1
Received: 14/12/04

Document Type: Interview Topic Guide
Version: 1
Received: 14/12/04

Document Type: Information Sheet
Version: 1
Received: 14/12/04

Document Type: Informed Consent Form
Version: 1
Received: 14/12/04

Document Type: Your response to the Committee’s Comments
Version: 1
Dated: 31/01/05
Received: 01/02/05
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Dr H Thomas, Supervisor, Dept of Sociology
‘Cultural Negotiations in Health and Illness: The Experience of South Asian Type 2 Diabetics’
Information Sheet

I am a social scientist at the University of Surrey. I am carrying out qualitative research in the Hindu Gujarati community on the experience of type 2 (non-insulin dependent) diabetes. In order to do this I am carrying out interviews with people who have this type of diabetes. I am interested in finding out about the experience of living with diabetes and am interested in hearing peoples' views in light of their own personal experiences. Interviews will normally be with one person at a time, but if respondents feel more comfortable with someone they know present, this would also be possible.

Taking part involves one interview with myself lasting approximately one hour. The interview will usually take place somewhere convenient to the respondent. Permission will be asked to use a tape recorder. I would like to use this information for my PhD research. I would also like to present findings from this study at conferences, and in published papers. You name or personal information will not appear at any time in any reference to this data, and your views will remain anonymous at all times.

Any information you provide is confidential and your name will not appear anywhere in any report related to this project. All data will be handled in accordance to the Data Protection Act 1998. All the data from your interview will be destroyed when no longer required. This study has been assessed by the University of Surrey Ethics committee, and given a favourable ethical opinion.

Withdrawal from the study is possible at anytime, including during the interview, without reason or justification.
Contact Details

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<tr>
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<td>01483 686968</td>
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APPENDIX C

INFORMED CONSENT FORM
Informed Consent Form

Thank you for agreeing to be interviewed for this study. Please read the Respondent Information Leaflet for general information about the study and the kinds of questions you may be asked. If anything is unclear please ask for further explanation before signing the form.

I, the undersigned, voluntarily agree to take part in this study on the ‘Experiences of South Asian Type 2 diabetics’.

I have read and understood the Information Sheet and have been given the opportunity to ask questions on all aspects of the study.

I understand that all personal data from this study will be stored and handled with the strictest confidence and anonymity, in accordance with the Data Protection Act (1998).

I understand that I am free to withdraw from the study at any time without reason or need to justify my decision.

I understand that if I so wish, I can ask for someone I know to be present during the interview.

I understand that this interview will be tape recorded and the interviewer will be taking notes, both of which will be used in the study.

I have read and understood the above information and I have read the respondent information leaflet.

I freely consent to be interviewed on the basis of the above.

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Interview Topic guide

Demographics / Intro questions
How old are you?
How long have you lived here?
Where did you come here from?
Which city did you settle in?

Diagnosis:
What kind of diabetes do you have?
How long have you known about the illness?
How was the diagnosis established?
How did you react to it?
How did your family react to it?

Nutrition:
Are there any changes to your diet that you could talk about?

Lifestyle
Are there changes to your lifestyle that you could talk about?

Help seeking:
What sort of medical care do you use for diabetes?
How has the care been since you were diagnosed with diabetes?
How do you feel when getting treatment for the illness?
Do you use any other form of help – friends, family, help groups?
Do you use any form of traditional help for diabetes?
When you are at home, are there any home remedies, foods, things that you do which you feel help to make things better?

What’s your feeling about how care is organised for ethnic minorities?
Could you tell me about how you feel this affects you / your community?

Living / Management with illness:
How does this affect your everyday life – how have things changed since your diagnosis?

What do you feel about all the different things you have to think about and attend to with this illness?

Could you talk to me about the changes to your life you have had to make because of the illness?
APPENDIX E

Coding Examples:

Code families

Interview transcript with Codes
Network View on: Diag_Food_Exerc

[Diagram of network view with nodes such as "Cause of Asian diabetes - food", "Food", "Food India", "Sweet stuff - blessing!", "Social eating - moderate", "Exercise", "Food was fine before", "Social eating - just say no", "I exercise in the home", "Indian food unhealthy", "How Found Out", "Double Check", "Changes to diet", "Food-Moderation", "Indian cooking - Disadvantage", "I'll eat what I want - I deserve it", "Food-effects on family", "Indians and food", "Eating Times", ""Balance your books!"].
Network View on: CAM/Herbal/

- Karela
- Don't use Herbal
- Turmeric
- Herbal-advantages
- Comp/Alter medicine
- Side effects
- Herbal-Disadvantages
- Knowledge of Herbal remedies
- Methi
- Ajmo
- Herbal

CAM/Herbal/
Network View on: Identity/adapting2

- Becoming "Multi"
  - Coming to the UK
  - Mixing with many people
  - Have my own resources
  - My training
  - Adapting to the UK
  - My history
  - Being in UK
  - Survival

- Adapting to life
  - Managing work
  - The older generation-WW2
  - Expertise
  - Life Before
  - Racism, abuse
  - Early experiences settling in UK
  - It's in my nature
  - Interacting with community
  - My strategy - I want to know

CF:Identity/adapting
Mrs KB, DOB 21/01/1922 T2, since 1987,

Lengthy talk of how there are people of many different religions and cultures in the family. Asks me about my surname, caste. I explain about informed consent.

I came here in 1982, from Kenya.

How first found out?
I was feeling some weakness, went to the doctor, he checked me, told me I had slight diabetes, and as the years went by, it went worse. I’m very careful with my food, no sugar in tea etc, but in rice and carbohydrates you do get some sugar, so... I exercise as well, cycling, up-downs (oot-bess), but walking is difficult because of the climate, and I’ve some problems with balance, as recently I fell in the bath. I was unconscious, for about 2 hours, then when I came round, I managed to get to safety, and call the doctor. He gave me flu tablets, I had fever, then two weeks after he told me I had hypothermia and pneumonia. So after this I became weak. So I don’t go walking alone right now, in case I fall, and break a hip bone, so now I exercise in the home.

First thoughts?
I didn’t think anything because my mother had diabetes, at the age of 30, well I got it very late, and the doctor said its not an inherited thing, its because your pancreas is not working. So it wasn’t a matter of fear. I used to be a teacher, I know I read the literature, and I had done half of my medical studies, but due to circumstances my father fell ill, and wanted me to get married, and left my studies. So I had good knowledge of all this. Even now I read medical journals, so what to do, not to do, the confidence to deal with diabetes I have it, I know what to do.

Have you always thought like this?
Its in my nature. If i get a headache, I go into the books to see why the headache is there, how should it be dealt with, what food should I take, avoid, I have a passion / interest / curiosity for it. Being a teacher, I was a science teacher, so naturally I had this curiosity to find out about these things.
So where did you study?

In India. My principal was a European, and the science teaching was very good. It was one of the best state schools, the medium of instruction was English so we don't have problems with this. From that I decided to study medicine, first I got a sponsorship to study medicine, then I did 2 years and my father fell very ill, I was the only daughter. His wish was to see me married, and I thought well what's the point of me being a doctor and my father dying? It wouldn't bring me happiness, so I sacrificed myself. I became a teacher instead, as you can't do much with half a degree. As a teacher I expanded my knowledge, in Nairobi, I was known as a "doctor without certificate". People from all over used to phone me and ask me "x, this has happened, what do I do, what medicine do I use?" I know I know desi medicine and other medicine. I came here in 1982, and got diabetes in 1987. Now even if I had a little diabetes, I wouldn't have known as I was never tested. But I was very very healthy when I came here. Then climate, and everyone gets affected at the beginning. Then the food, in the cold you feel like eating sweet stuff, so then I started eating chocolates etc. people used to say to me I'll get diabetes, and used to say to them the day I get it I'll stop - I have a very strong will. Today I've stopped. If I feel like I'm feeling the need, I'll have a small piece. When I fell I hurt my head and it carried in hurting, so someone told me you should take tobacco snuff, so the head pain will stop. So for 3 months this woman gave me the snuff, and I took it. Then I thought "this is a bad habit I'm creating", the headache isn't going away, it goes for a short time, then I have to take more. So one day I threw it away.

It was no problem?

No problem! If tomorrow someone says to me I have to live in a small hut, then I'm ready. I used to live in a 6 bedroom bungalow built by my husband, so when I came here to a small flat, I could've thought what's this. But I go according to circumstances.

Why do you think you can adapt to these situations?

Oh, yes, anything I can adapt to. My parents trained me to be that way. The street we lived in there were hindus,
muslims, everyone there. And to everyone my mother was their aunty and I was their sister. If children were ill they would come to us for medicine, if they wanted pickle they would come to us, clothe making, for weddings for example. This is how we were raised - help anyone who needs it, from morning till night, just do 1 good thing for someone, so that you never think the day was a wasted one. Any my husband was very cooperative. I had to stop work, as I had a brain tumour, and a swami told me there's no need to have an operation, the tumour will go, you have to start the process of seva (devotion). Until today I haven't had an operation. European doctors diagnosed me with brain tumour. I went into hospital and because I feared for my daughter being left without a mother I took some treatment. But since then I had no trouble. My swami told me the day I want to die, I should stop my devotion, I'll be dead in 6 months. So I don't stop seva, small large.

Some talk of early childhood.

All I used to ask from god was that my children be given such a strong educational background that they can stand firm and earn their way in the world. Talk of childrens' jobs and lives.

Apart from education there I have no other main value in life.

Most difficult?

Figuring out whether levels are high or low. When its too much, my urine goes a dark colour, and I feel a giddiness. When its too low I feel like eating sweet stuff, and feel giddy, but that's a different type of giddiness. That's how I know. If its low, I'll take some sugar, or drink, or lemon, sugar and salt solution, if its too much, then the next day all I have is my breakfast of cornflakes and milk or bread. So my diet becomes regulated. But whatever happens I take my medication.

Medication - ok?

One tablet I was taking was causing too much constipation so now I've changed. I also take blood thinning tablets. We'd eaten so much ghee, the blood became thick. (shows me medications)
Herbal remedies?

I take methi in the morning. Firstly I take a quarter spoon turmeric, with warm water, then in another glass a quarter spoon methi, and in a third glass quarter spoon ajmo. So in the stomach the gas is lessened. As we get older the digestion power is weakened, so food isn't digested as easily. And I eat less now - I don't eat to a full stomach anymore, if I want 2 chappatis, I eat 1 and half, if I'm hungry for 1 and half, then I'll eat one. But I'll eat my curries, because that's where I get my greens, for stamina. We don't eat eggs, so where else do we get stamina? And I eat yoghurt, everyday, yoghurt, cheese and milk.

Methi and ajmo and turmeric - feel a difference?

Look, turmeric is an antibiotic. So I don't need to take antibiotics. Otherwise a lot of the time for diabetics they have to take this and that, but with me where I have been hurt, it won't go infected, otherwise usually if you get hurt, you have to take an anti-biotic. Now I burnt myself about 5-6 months ago, I had my coat on and it stuck to my arm, now it would usually become infected, but with me no, so the antibiotic is there. Now methi is bitter, so it gets rid of xxx (inaudible), and ajmo lessens gas and helps digestion.

What about karela?

Yes, I used karela juice; it suits some people and doesn't suit others. I tried it, and for a long time my eyes would water. What I did was I crushed karela skins, and made them into cubes, so everyday I would pop one cube in hot water and drink it. I did this for about 1 and half, 2 months. Then my eyes were watering heavily. So I met one ma-ji (an elder woman), and I asked her why do you think this is happening? She said your not drinking karela juice are you? She said I had the same thing. Stop the karela juice, I did and within a few days my eyes stopped watering. So certain things are suited to ones body, and certain things are not. You have to be your own doctor and treat your body in a way which pleases you. Up to now I have no insulin, but in the future who knows? Even my kidneys are ok, my liver is ok.

Active in the community?
48 Oh yes!! Even in the home I’m very active. Because (here there is a conversation which would undoubtedly identify this woman. I have not transcribed this, as it involves activities pertaining to other people in the community. It involves helping people in the community. Lengthy conversation of Hinduism. Also more conversation about community activities which would identify her - started a community event which has now been transferred to official status.

49 All my neighbours are Muslim, when they come in I greet them in their custom greeting, and they greet me in my custom greeting. People often ask me “have you changed religion? Or have you made them into Hindus?” and I say to them yes, they have become Hindus and I have become Muslim. This is the only way we are able to live, we have to live with one another in this world. Because you see my father was working under the Europeans, and they used to come to our house to eat, and of course it was a very mixed environment. We became “multi”. We kept our customs in eating and drinking, and if people eat meat then we would be seated separately, but it was always with love.

50 Lengthy conversation about her charity work, her work on tv documentary, fees she earned for charity. Again this would identify her.

51 Do you worry about your diabetes when on trips, doing charity work away?

52 No, I take my food from home. Breakfast, lunch, dinner, tea, coffee I take myself. I look after myself. Tomorrow if something happens to me, well God only knows, but today I’m looking after myself.

53 Ever worried about health?

54 No, never worried. Once I have 5 complications in the stomach. God is with me, my faith is strong.

55 Lengthy talk of her son, then some events which would identify her.

56 I came here on 30th October when it was snowing! People said don’t go now, I said no I must go now to get used to it. My father pushed me to be courageous.
Hospital care, clinic, what do you think?

Fine. But recently I found the medicine has had reverse effects on my body - so I went to the doctor and I said I don’t want any medicine apart from diabetes medicine. Herbal medicines haven’t got reverse effects, these have. You know we say about Mahabharat, I said if it (biomedicine) goes into my body there will be mahabharat in my body. So I don’t want any war now. When I did not understand I took it, but now I understand that it has given me reverse effects I stopped it.

Searches for material to show me. Main interview ends here, but our conversation continues.

END