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**RISK PERCEPTION AMONG OLDER
SOUTH ASIANS WITH TYPE 2
DIABETES IN THE UNITED
KINGDOM**

LEAH MACADEN

PhD

August 2007

**RISK PERCEPTION AMONG OLDER SOUTH ASIANS
WITH TYPE 2 DIABETES IN THE UNITED KINGDOM**

LEAH MACADEN M.Sc (N), RN, RM

*A thesis submitted in partial fulfilment of the requirements of
Northumbria University Newcastle upon Tyne, United Kingdom
For the degree of Doctor of Philosophy*

**Research undertaken in the School of Health, Community and
Education Studies
Northumbria University, Newcastle upon Tyne
United Kingdom**

August 2007

ABSTRACT

RISK PERCEPTION AMONG OLDER SOUTH ASIANS WITH TYPE 2 DIABETES IN THE UNITED KINGDOM

South Asians living in the UK have an increased predisposition to developing Type 2 diabetes. Type 2 diabetes usually occurs later in life and has significant invisible long term risks that can affect an individual's quality of life and longevity but are preventable with life style changes. For people of South Asian origin, their perception of risks associated with Type 2 diabetes is likely to be shaped by a range of different factors, including cultural influences on gender roles, family life, and the significance of food and its preparation. The South Asian population in the United Kingdom is heterogeneous with strong socio cultural and religious beliefs that impact upon an individual's life style.

Research on issues related to risk and risk perception have largely been conducted in developed countries. Models on risk perception have also evolved from these settings where people have increased personal autonomy, better resources and access to health care and related information. Risk is socially constructed and is influenced by socio cultural factors, religious beliefs and gender. Health related risks are understood differently by lay people and practitioners. Research available on risk perception among minority ethnic groups and the immigrant population living in a western context is very limited. Risk perception among South Asians with diabetes has not been explored in particular despite the escalating incidence of Type 2 diabetes in this population. This study aimed to explore how risks related to diabetes were perceived by older South Asians with Type 2 diabetes in the United Kingdom and developing a conceptual model on risk perception.

A qualitative research design using grounded theory with its theoretical foundations drawn from Symbolic Interactionism was used. Data from two focus group interviews with ethnic health development workers, seven individual interviews with practitioners and twenty interviews with older South Asians with Type 2 diabetes was collected, transcribed and analysed. The process of Cross Language interpretation (Larson 1998) was used with gender and ethnically matched interpreters to collect data from non English speaking participants. Triangulation, audit trail, peer debrief and reflexivity were used to enhance rigour in the research process.

Risk perception among older South Asians was interpreted in terms of risk awareness and risk engagement. Risk awareness was influenced by factors from within the cognitive and affective domains that resulted in risk engagement. Risk engagement was proactive if risk awareness was present and the locus of control was internal. Risk awareness involving the affective domain resulted in reactive risk engagement through risk response, ranking of risks, risk repair and creation of safety nets when influenced by external locus of control. The affective domain being predominant in comparison to the cognitive domain poses significant implications in the planning and provision of services to minority ethnic groups.

The concept of concordance in diabetes management and the empowerment model that advocates self management towards risk prevention as the cornerstone of diabetes management may be challenging for both South Asians and their practitioners. This model on risk prevention that is largely oriented towards the cognitive domain requiring internal locus of control needs to be carefully evaluated in minority ethnic groups such as South Asians with Type 2 diabetes.

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My sincere gratitude goes to Northumbria University for offering me a studentship to be able to work towards a doctoral degree. I would like to particularly acknowledge Dr. Colin Chandler as the Director of Postgraduate Programmes at the University and Lorna and Julie in the School of Health, Community & Education Studies for their friendly, constant and willing administrative support.

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Finally, I thank God for His faithfulness and blessings in seeing this project to completion.

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

Name: Leah Macaden

Signature:

Date: 10 August 2007

CHAPTER: 1

INTRODUCTION

Evolution of the research idea

This doctoral thesis is entitled “Risk perception among older South Asians with Type 2 Diabetes in the United Kingdom.” I had the invaluable opportunity of coming over to the United Kingdom (UK) on a three year study leave that is given to the faculty from my institution in India and had initially worked towards obtaining my registration from the Nursing & Midwifery Council (NMC), UK to work in a clinical setting as a Registered Nurse which was successful. Subsequently, I also made contact with the Northumbria University in Newcastle upon Tyne to explore research opportunities and expertise to refine my research skills and gain experience in doing Qualitative research. An opportunity to work towards a PhD studentship was pursued with success and this thesis is an outcome of the PhD work that was undertaken.

In the course of my practice as a Registered Nurse in North East England, and while exploring areas to be researched that would have significant relevance to both the UK and India, I had interestingly come across clinicians who expressed serious concern over the difficulties that health professionals in the UK had with understanding the South Asian culture and practices in relation to their diabetes management and prevention of long term risks.

Type 2 Diabetes tends to be asymptomatic until quite late and people are often diagnosed to have Type 2 Diabetes in retrospect when they present with a complication or a risk that has resulted from this long standing disease. It was also observed from the researcher’s practice over the years (both in India and the UK) that patients who presented with long term risks due to diabetes were often unaware of the life style changes that were required to prevent them. Despite education and

information, diabetes isn't perceived to be a serious illness due to the lack of visible evidence of the proposed risks until they actually happen.

From the literature review that was undertaken, it was observed that research on issues related to risk and risk perception have been considerably explored in the Western countries. However, research available on risk perception among minority ethnic groups and the immigrant population living in a western context is very limited. Risk perception among South Asians with diabetes has not been explored in particular despite the escalating incidence of Type 2 diabetes in this population. Risk in general is a challenging concept because of its abstract nature and I was interested to explore how risks related to diabetes were perceived and the basis with which South Asians made their choices in a western context. This was crucial to explore since the choices available, availability and access to resources and the power to make decisions impact upon risk perception (World Health Organisation, 2002b). I was interested in the topic chosen because of my professional background (Nursing) and my personal interest in chronic disease in older people and diabetes in particular.

Background of the researcher

I am a nurse by background with a Post Graduate Degree in Nursing and have been involved in Nursing Education and Practice over the last 15 years in the Christian Medical College, Vellore, South India. The College of Nursing of this institution has an international reputation and has been a pioneer with most Nursing education and Practice developments within the country over the last 60 years. The Nursing Research literature available in India is very limited. Qualitative research approaches are also fairly recent in the country in spite of their appropriateness and relevance for nursing research.

Background of the research

Type 2 diabetes is common among minority ethnic groups such as the South Asians in the UK. It is a chronic disease that commonly occurs in later life, and can affect many facets of the individual, as well as his or her family and the community. The individuals affected may be required to make major changes in their diet, have regular exercise, attend regular medical check ups, adhere to long term medications and comply with all the advice for life style changes given by the health professional. People can view this as an intrusion imposing restrictions on their lives. It can lead to decreased quality of life, increase in mortality and acute metabolic complications.

The priorities in an individual's life and lifestyle practices especially in relation to food, religious observances and physical activity often have strong socio cultural and religious influences in the South Asian community. For example, it is not uncommon among South Asian Muslims with diabetes to fast during Ramadan because of their religious values and beliefs.

Planning and delivering health care services requires sound understanding of the underpinning culture especially for chronic diseases such as diabetes. People from different cultures and social groups may have different health care philosophies (Helman, 2000) and practices with varied expectations from the health care system. Knowledge of cultural variations and health care beliefs facilitates the provision of culturally sensitive services in addition to making patients feel valued and empowering health care providers (Pawa, 2003).

Type 2 diabetes poses serious long term risks such as renal dysfunction, cardiovascular risks and peripheral vascular risks that are preventable with optimal management of the disease and life style changes. South Asians residing in the UK are at least four times more vulnerable to developing Type 2 Diabetes when compared to the general population (D'Costa et al., 2000). They are also predisposed to developing complications ten years earlier on and associated with increased mortality by 40% in

comparison to their white counterparts (Raleigh et al., 1997). Social and cultural influences among the South Asian population are also important factors in addition to their genetic susceptibility to the disease (Greenhalgh, 1997).

Risk can mean a probability, a factor that raises the probability of an adverse outcome, a consequence or a potential adversity or threat (World Health Organisation, 2002b). Health related risks have been largely defined from a scientific perspective despite the awareness that risks are understood and interpreted differently by different groups. During the 1980s, scientific predictions of risk were considered to be ‘rational, objective and valid’ as opposed to lay perceptions that were believed to be ‘subjective, ill – informed’ and hence less valid (World Health Organisation, 2002a). There has also been a paradigm shift especially with risk management in chronic diseases since risks were characterized as behavioural in origin and hence largely under individual control. This in turn led to advocating lifestyle changes and health promotion strategies that were aimed at risk prevention.

Individual perception of risks and the autonomy that one has to control those perceptions are largely governed by the concepts of risk that are actually embedded within the individual’s society and culture (Douglas et al., 1982). Past experiences, spirituality, communication and awareness through media, interaction with family members, peers and other social groups enable and assist people to form their values. The individual’s society and culture, including references to beliefs and systems of meaning also facilitate this process. The assimilation and the organization of all this knowledge, starting in early childhood, guide the individuals to develop world views and make sense of their world. These world views include beliefs such as fatalism towards control over risks to health and belief in hierarchy and leaving decisions to the experts which have been significantly linked to lay perceptions of health related risks (Peters et al., 1996).

The “language of risk” is not the same between patients and practitioners. Therefore, it is necessary to explore the possibilities to standardise this in order to improve risk

communication with patients. This may be challenging since risk construction is individual and context specific. It would therefore be valuable for practitioners to be knowledgeable about peoples' risk experiences, the meaning they attribute to risk and their beliefs. Good risk communication will also facilitate the possibility of making 'informed choices' and keep up with the current trend of improving patient's choice in healthcare (Walter et al., 2002) and the empowerment model of health care (Meetoo, 2004). Empowering patients is aimed at maximising an individual's potential for health and wellness resulting in the development of skills, attitudes and self awareness that would positively influence health behaviour in the individual.

Risk in general is a challenging concept because of its 'slippery' (Marais et al., 2006) and abstract nature. Assessing how people perceive risks is often a difficult task since its interpretation is individual and context specific. People are often inclined to reflect the questions posed, back to the researcher and seek clarification. Risk that is not visible especially is not something that can be directly measured or quantified easily. The researcher was therefore interested to explore how risks related to diabetes were perceived and the basis with which South Asians engaged with risks related to their diabetes.

India, China and the U.S. will have the largest number of people with diabetes by the year 2025. It has been estimated that 300 million people will have diabetes by the year 2025 which is around 5.4% of the world's projected population (International Diabetes Federation, 2003). The reasons for this escalation are due to changes in lifestyle, increased longevity and a sedentary life that is stressful. Diabetes management involves an active health promotion component and that is very much possible within the scope of nursing.

Health promotion is complex, diverse and multifaceted (Norton, 1998). It is about individuals receiving information, assessing their personal risk and then making choices (Blinkhorn, 1995). The choices that patients make appear quite sensible if one understands the demand characteristics of their environment. For example, the focus

group research among Latinos with diabetes highlighted the pressure that the Latino women feel to put the priorities of their family ahead of their own (Anderson et al., 1998a). Making dietary modifications to care for one's diabetes in such a milieu is extraordinarily difficult. There is also plenty of literature available in relation to problems associated with having diabetes from the perspective of health professionals (Koch, 2000) but few that are from the perspective of the person living with the illness. However, several authors have recommended research which would enable health professionals to understand patient's perspectives of living with diabetes (Anderson et al., 1991; Ellison et al., 1998; Hernandez, 1995; Mitchell, 1998).

Lack of knowledge about any culture and their practices in relation to health and illness can predispose to generalization and stereotyping. The challenge that also lies ahead does not just involve caring for people with diabetes but also to include factors such as healthy lifestyle and its impact on the prevention of non communicable diseases such as this in the development of the nursing curriculum (Hjelm et al., 2003) and other related professional education. The project will also therefore allow recommendations to be made for both education and practice settings, given the magnitude of the problem with diabetes.

Aim of the investigation

To develop a conceptual model on risk perception among older South Asians with Type 2 Diabetes in the United Kingdom.

Objectives

- To identify the factors that influence risk perception among older South Asian men and women with Type 2 Diabetes.
- To identify gender variations in the perception of risks related to Type 2 Diabetes.
- To identify patient practitioner variations in risk perception.

An overview of the research methodology, research design and methods

Robson's framework for research design was used as outlined below (Robson, 2002a).

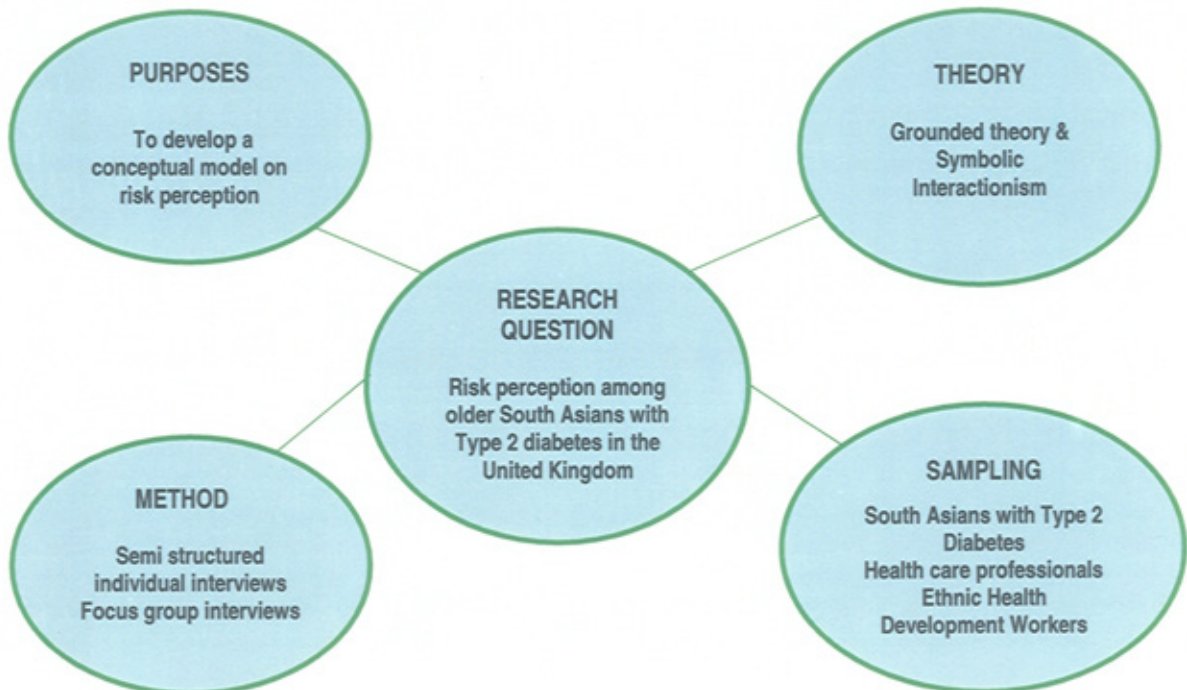


Fig 1. Framework for research design

A qualitative research design using grounded theory with its theoretical foundations drawn from Symbolic Interactionism was used. Data was collected from two focus group interviews with the Ethnic Health Development Workers, seven individual interviews with healthcare professionals and 20 interviews with South Asian men and women (with ancestral origins from Bangladesh, India and Pakistan) who live in the UK with Type 2 diabetes. Representations were sought from non-English speaking groups. (Nine out of the twenty interviews were from the non English speaking group). Interviews with these nine participants were done using the Ethnic Health Development Workers (also from the South Asian background) as interpreters and the Cross Language interpretation process (Larson, 1998).

All the interviews were digitally recorded and transcribed, and returned to the respondent for validation wherever possible. Issues related to validity and rigour were addressed using triangulation at two levels (data and interdisciplinary)(Robson, 2002b), reflexivity (Ahern, 1999), peer debriefing and maintaining an audit trail (Cutcliffe et al., 2004). Data was managed using NVIVO 2, a Qualitative software package.

Outline of the thesis

The first chapter of the thesis outlines the researcher's experiences, the conception and evolution of the project, aim and objectives of the study and concludes with an overview of the research methodology, research design and methods.

The second chapter on literature review deals with an introduction to the various resources accessed and referencing using End Note 7 a bibliographic manager, the process of ageing, Type 2 diabetes as a long term condition, its epidemiology, compliance versus concordance, risk perception, socio cultural practices among South Asians and diabetes related risks in the UK South Asians. It also describes in detail about the locus of control and gender issues in relation to risk perception and outlines the UK policies and practice in relation to diabetes management.

Chapter 3 is a synthesis of the methodology and methods used in this study. It describes in detail the process of how Grounded Theory and Symbolic Interactionism were used, the research design, methodological issues identified and addressed, the process of sample selection and recruitment of participants and compliance with ethical requirements. The chapter also describes the processes of data generation, data management and the development of data analysis and the methodological decision making at each stage with details and worked examples of the application of the theory in practice.

The fourth chapter outlines the development of data analysis in detail using the principles of theoretical sensitivity, constant comparison, different levels of coding and categorising resulting in the development of the conceptual model on risk perception.

The fifth chapter describes the influence of cognitive domain influencing risk perception among older South Asian men and women with Type 2 diabetes and broadly classifies them under religion and spirituality, understanding of diabetes, impact of diabetes, perceptions on the severity of their diabetes, their personal experience with diabetes related risks and issues around management of diabetes.

The sixth chapter highlights the significant socio cultural factors among South Asians such as culture, gender, perceptions on ageing, family dynamics, hospitality and travel back to their country of origin and the influence of affective domain on risk perception and the heterogeneity within the South Asian culture. A small section focuses on the gender variations in risk perception among older South Asian men and women.

Chapter seven primarily describes issues around locus of control and significant variations with which risks related to diabetes are perceived between patients and practitioners. This is also one of the objectives of this study and the variations are discussed under the cause of diabetes, management of diabetes, perception of severity, barriers in diabetes management, priorities and risks related to diabetes and the locus of control.

Chapter eight focuses on risk awareness and risk engagement among this population. The evolution of concepts such as risk awareness, proactive and reactive risk engagement, risk response, ranking of risks and risk repair that emerged from the data within this study are described with examples.

Chapter nine outlines the way forward as expressed by practitioners and South Asians towards practice and service provision and education.

Chapter ten deals with the discussion from the results in detail in the light of similar research and describes the conceptual framework that was developed from this study. The various factors that influence risk perception among older South Asians with Type 2 diabetes are contextualised with a model on risk perception. The model explains risk perception in terms of risk awareness and risk engagement.

Chapter eleven is the concluding chapter that critiques the study, describes contribution to knowledge and the implications for Practice, Education & Policy in the light of the findings from this study.

These eleven chapters are then followed by references, appendices and copies of the two papers that were published from this study.

CHAPTER: 2

REVIEW OF LITERATURE

Introduction

The literature review for this study was undertaken in several areas since there were multiple components to the study. The areas that were primarily reviewed were the ageing process, Type 2 diabetes, chronic disease and long term conditions, the South Asian perspectives on culture and health beliefs, the concept of concordance and the current UK policies in relation to diabetes management. An extensive literature review was also undertaken on issues related to risk and risk perception as influenced by health beliefs, culture, gender and religious practices in detail since that was the primary focus of this study. The journals that were accessed extensively were the Journal of Advanced Nursing, Journal of Clinical Nursing, Ageing & Society, Geriatrics and Gerontology International, International Journal of Older People Nursing, Risk Analysis, Health, Risk and Society, Diabetic Medicine, Practice Diabetes International, Journal of Diabetes Nursing and The Diabetes Educator, to name a few. An Electronic Table of Content (ETOC) was set up for all the relevant journals in order to keep up to date with the current literature and the journals were reviewed regularly as they were published. This also ensured efficient time management with the literature review process.

Several bibliographic databases were searched electronically and the most frequently accessed electronic journal collections were from the MEDLINE, Cambridge University Press Journals, Blackwell Publishing of Synergy, EBSCO EJS, Ingenta Connect, Proquest Nursing Journals, Science Direct (Elsevier Journals), SwetsWise and Wiley.

Referencing is a very crucial part of the literature review and End Note 7 was used to facilitate this process. End Note 7 is a bibliography manager which enables the entry of bibliographic data from a variety of media such as books, articles and electronic resources, search for entries by author, subject, type or keyword , export

bibliographic entries into a word processor such as Microsoft Word, reformat entries in Word according to different bibliographic styles such as the Harvard or Author Date style and import entries directly from online resources (EndNote, 2006).

This chapter describes information from the literature reviewed on the process of ageing, Type 2 diabetes as a long term condition, its epidemiology, Type 2 diabetes in the UK South Asians, socio cultural factors such as health care beliefs, perceptions on ageing, communication barriers, religion and socio cultural practices among the South Asians; It also describes in detail about risk perception and the locus of control and gender issues in relation to risk perception. The UK policies and practice in relation to management of Type 2 diabetes in the context of 'risk' are also outlined.

Ageing

Ageing can be defined as a life-long process of progressive change in the biological, psychological and social structures of an individual. 'Ageing' commonly refers to those aged 60 years and above. Although 'ageing' is usually associated with mental decline and physical impairment, this is a misconception, as the majority of older people desire to enjoy good health and lead active lives. The functional capacity of biological systems may decline with ageing but the health and activity in older age are largely determined by the opportunities and activities of an individual across their whole life span (Stein et al., 1999). This in turn enables individuals to influence how they age by adapting to ageing-associated changes and by adopting healthier life styles.

Life expectancy has improved subsequent to the sharp decline in premature mortality from many communicable and non-communicable diseases. This has been possible due to improvements in sanitation, housing, and nutrition as well as to medical innovations, including vaccinations and the discovery of antibiotics. Life expectancy is expected to continue to rise in virtually all populations throughout the world leading to a steep increase in the number of people reaching older age (Stein et al., 1999).

The sharp increases in life expectancy have been followed by substantial falls in fertility world-wide in developed and developing countries mainly due to the availability of modern contraceptive methods. In India, for example, Total Fertility Rates (TFR) - that is, the total number of children a woman is expected to have at the end of her reproductive years - have decreased from 5.9 in 1970 to 3.1 in 1998. This demographic transition from a pattern of high mortality/high fertility to that of low mortality/low fertility, is commonly referred to as 'population ageing'. There are currently about 580 million older people (60 years and above) in the world, with 355 million in developing countries. By 2020, the figures are expected to reach 1,000 million, and over 700 million, respectively (World Health Organisation, 1998). It is projected that in countries with fertility rates below replacement level, the proportion of older people will exceed the proportion of the very young by 2050. This will also increase the proportion of older people in comparison to the very young by 2050. Serious implications due to this are predicted for the future. For example, one child may have to care for several elderly relatives, and the 'younger old' may be looking after the 'older old' (Stein et al., 1999). This may also pose several challenges within the South Asian culture where multigenerational family members live together as the same household.

Rapid population ageing poses immense challenges to health care and social services. With the increasing proportion of older people, the incidence of people developing Non-Communicable Diseases (NCDs) and the associated disability will also escalate. NCDs including cardiovascular diseases, diabetes and cancer are predicted to be the main contributors to the burden of disease in developing countries by 2020 (Murray et al., 1996) and will be responsible for over three quarters of all deaths.

Health professionals also need to be aware of and sensitive to the multiple perceptions of health and health beliefs shared by people from different socio cultural and linguistic backgrounds (Daly et al., 2002). This rapid increase in the elderly population across different countries and cultures also demands that scientists identify, appreciate and acknowledge similarities and differences in ageing among different groups of people through research (Whitfield et al., 2000). The similarities across cultures will provide information and support for the universal nature of ageing

irrespective of peoples' cultural diversities. The differences in ageing among ethnic groups in particular will help us to identify and understand the factors that influence perceptions of health and illness and the choices that individuals make in their given context. It would also promote the practitioners' ability to provide care that is culturally sensitive.

Type 2 Diabetes

Epidemiology

Diabetes mellitus (DM) has become a seriously threatening global health problem, and is reaching epidemic proportions worldwide with serious implications for morbidity and mortality (Zimmet et al., 2001). It has been estimated that 300 million people will be affected with Diabetes by 2025 (World Health Organisation, 1997). The most vulnerable groups to this pandemic are populations of developing countries, minority ethnic groups and socio economically disadvantaged communities in industrialized countries (King et al., 1993; Zimmet, 2000). 'New world syndrome' as it has been termed (Zimmet et al., 1997), seems to be a symptom of globalization with its social, cultural, economic and political significance (Zimmet, 2000). The pandemic involves essentially non insulin -dependent diabetes mellitus (Type 2 DM), which comprises about 85% of all diabetic cases (Zimmet et al., 1997). Apart from the impact on health, this epidemic has significant implications in terms of cost for both the health care industry and the society (Zimmet, 2000). If this trend continues, diabetes will constitute a heavy burden both for individuals affected, their families and for the societies in which they live (Zimmet et al., 2001).

Type 2 Diabetes as a long term condition

Chronic diseases may involve physical or mental impairment and often demand designing daily living, around symptom management. They also represent a loss of integrity—the wholeness of the individual when any part of the body does not function properly. There is a sense of regret for not only the loss of their present

capacities and roles, but uncertainty and anxiety about the loss of their future ones as well (Kenen et al., 2003).

Long term conditions such as diabetes also seem to impose biographical disruptions causing disturbance in social relations and self identity. The day to day routine and structure get disrupted. These disruptions have symbolic as well as physical, social, cultural, financial, relationship and medical meanings to the individual affected and can have a significant bearing on feelings of self-worth (Bury, 1982). There has been an upsurge of interest in embodiment, recommending a more bodily approach to long term conditions (Williams, 2000). Physical and biological factors in an individual with long term conditions also impinge upon self, stimulate a need for identity reconstruction and affect social interaction (Williams, 2000).

Long term conditions tend to disrupt daily routine and structures, the usually 'taken for granted' features and the practical knowledge on which the individual's experiences are based (Williams, 2000). Any long term condition imposes practical consequences for individuals and their families. It places demands on time for the management of symptoms and medical treatment, causes disruption at home / work place and also has socio economic implications for the long term management of the disease. The meaning of long term conditions may be seen to reside in its symbolic significance. Different illnesses carry with them different symbolic significance within different cultures and have a bearing on how individuals regard themselves (Bury, 1988). Long term conditions are also associated with many uncertainties in terms of diagnosis, symptoms and prognosis.

Diabetes in particular is managed by monitoring blood glucose, daily exercise and diet restriction but with minimally noticeable change on a short term basis. Individuals tend to use coping as a cognitive process where they learn how to accommodate the effects of long term conditions in their lives. Given the disruptive features of long term conditions, people try to get on with their lives by 'normalising' the whole process. In their attempt to cope, they 'bracket off' the impact of the illness so as to not let it affect their identity (Kelleher, 1988).

Individuals consider diabetes as something to be expected after a certain age especially if they have a strong history of diabetes within their family and tend not to view it as an illness. Since the symptoms of the disease are not very obvious or visible and it also involves aspects such as diet, physical activity and weight reduction affecting one's life style and their families, individuals with diabetes are inclined to carry on with their daily routine avoiding reminders about the disease as much as possible. This is also due to the lack of understanding of the relationship between poorly controlled diabetes and its effect on someone's heart, kidney or eyes since the patho physiological changes are vascular and internal. In the early stages of the disease where the individual does not get incapacitated or feel unwell, it becomes legitimate to normalise the whole process and "bracket off" the long term impact of the illness.

Hyperlipidemia, hypertension, peripheral vascular disease, blindness, nephropathy and neuropathy are some of the potential consequences of living with diabetes. (Dunning et al., 1998; Haas, 1993; Hendricks et al., 1998; Heyman, 1998) . People with diabetes face a complex management problem of their disease because of the nature of the disease. The individual is likely to develop psychological stress from living with the risks arising from diabetes (Armstrong, 1987) leading to feelings of fear and uncertainty (Charmaz, 1983).

People with diabetes develop adaptive cognitive and behavioural strategies to 'make sense' of their situation and 'keep going' with their lives (Ternulf-Nyhlin, 1990). People with diabetes try to limit the impact of living with risk through attempted normalisation (Robinson, 1993). It is therefore crucial to achieve and maintain a balance between quality of life and adherence to a medical regime.

Compliance versus Concordance and Type 2 Diabetes

Compliance is a key concept especially in chronic illnesses such as diabetes. It represents adherence to the recommended treatment regimen and is crucial to measure outcomes in medical care. Failure to adhere with treatment results in complications (risks) due to poorly controlled diabetes. Greater compliance is associated with a decreased probability of diabetes related complications (Harris et al., 1985). Non compliance on the other hand leads to diabetes related risks that impose significant financial burden on health care systems and personal costs to the individual with diabetes (Royal Pharmaceutical Society of Great Britain et al., 1997). Monitoring non-medical parameters such as diet, exercise, and periodic medical monitoring in the management of Type 2 diabetes mellitus is essential to prevent long term risks. Personal, social, demographic and clinical factors contribute to non compliance which can be intentional or unintentional (Chatterjee, 2006). Complexity of treatment, barriers to access services, an unsupportive social environment, and the extent to which an individual's everyday life is affected are some of the factors associated with non compliance (Jezewski et al., 2002).

The disruptions caused by Type 2 diabetes in an individual's day to day life tend to predispose to inadequate compliance with prescribed treatment and the effective management of any chronic disease and is by no means unique to diabetes. Patients with chronic disease have been observed to miss scheduled appointments for treatment 20 – 50 % of the time with 50 % of patients not taking prescribed medications and even a lesser proportion of people following the recommended changes that are required for effective management of the disease (Rosenstock, 1985).

In a study on home care of patients with diabetes, 80% of 60 diabetic patients did not administer their insulin in an acceptable manner, 73% of them did not follow their diet, 50 % exhibited poor foot care and 45% did not do their urine testing accurately (Watkins et al., 1967). Findings from other studies have shown that the dietary compliance is in the 10 – 35 % range. In the light of these statistics, one would tend to assume that health related activity and life style changes in the management of chronic

disease are not very popular. The issue does not seem to be due to any lack of interest in health or reluctance to manage the disease but rather an inability to be adaptive to the recommendations made by health professionals for various reasons. There seems to be a desire among patients that just taking the medicines that are prescribed should be sufficient rather than having to modify their lifestyle to effectively manage their chronic disease.

Despite the individual's ability to initiate life style modifications that are required for the management of diabetes, it is often difficult to sustain and achieve compliance. This has been described as "relapse" in the literature. A "relapse prevention model" (Rosenstock, 1985) which is a self control programme designed to teach individuals to anticipate and cope with the problem of relapse while they are trying to modify their life style as recommended seems to have great potential to maintaining diabetic regimens. Relapse prevention begins after a person has either initiated or abandoned some behaviour as recommended. It deals with maintaining behaviour that has been initiated rather than initiate the behaviour change itself. The major obstacles to sustain behaviour change seem to be negative emotional states such as anger or frustration, interpersonal conflicts (disagreements with family members) and social pressures (fasting during Ramadan, sweets being offered while visiting friends or family etc). The extent to which individuals relapse depends on their self efficacy. Individuals experiencing negative emotional states, conflicts, social pressures and role related pressures are at high risk of relapsing to a former undesirable behaviour.

For instance, a woman with diabetes who has commenced walking as part of her regular exercise regimen may decide to opt out if there are other priorities related to her family that come up in the way of her exercising. If the discouraged behaviour (lack of exercise due to other priorities) offers positive outcomes (appreciation from family members for fulfilling other roles) for the individual, relapse is quite common. It is crucial that the individual is supported through the relapse and made to understand that occasional slips are not avoidable and that it does not signify permanent failure. A number of strategies such as provision of information, access to

guidance when required and modifying health related behaviour through social support can be used to cope with the relapse situation.

Health professionals often have difficulty in understanding non compliance among patients. There has been evidence from research to show that physicians overestimate the level of cooperation achieved in their practice and also tend to blame the patient's personality for their lack of adherence with the prescribed treatment. There is often a rational basis for non compliance from the patient's point of view (Rosenstock, 1985). For instance, quite often, an individual diagnosed with Type 2 Diabetes is unlikely to be feeling visibly unwell except for generalized weakness and fatigue until the time of diagnosis. When this individual is started on Metformin, an anti diabetic agent for better glycaemic control and effective management of the disease, he or she is likely to develop gastro intestinal disturbances and diarrhoea which are side effects of the drug and subsequently feel quite unwell. He or she associates the drug as contributing to a reduced sense of wellness and tends to discontinue it, since that is a rational choice in his or her mind. It is also debatable that "perfect" compliance may guarantee prevention or worsening of the diabetes.

Psychological dispositions such as health beliefs, beliefs about the usefulness of the prescribed treatment and knowledge and rationale of the regimen are generally positively associated with compliance. Situational demands such as complexity of the required action, duration of the treatment and the extent of intrusion into people's lives tend to be negatively associated with compliance (Rosenstock, 1985).

For compliance to be measured with sensitivity and specificity, direct observation of the recommended treatment regimen (medications, adherence to diet etc) in the management of diabetes becomes essential which becomes impractical for obvious reasons. However, indirect methods such as self reporting (Questionnaires) and interviews to measure compliance can be used with success to measure compliance (Haynes et al., 1980). In an attempt to improve patient compliance, research on socio demographic and clinical variables as predictors of non compliance demonstrated poor correlation (Royal Pharmaceutical Society of Great Britain et al., 1997). Impaired

communication between the health care professional and the patient is often at the heart of the problems that lead to non compliance (DiMatteo, 1985). As demonstrated clearly, management of diabetes towards risk prevention is more than just compliance with the treatment advised or the lack of it.

In an attempt to improve understanding of the factors that affect compliance, a collaborative project by the UK Department of Health and the Royal Pharmaceutical Society of Great Britain led to the evolution of the concept of concordance (Chatterjee, 2006). Concordance encompasses the idea that there is no hierarchy in the doctor patient relationship in that both are equal partners and the patient is facilitated to make informed decisions. It is based on the premise that there would be an open exchange of beliefs around diabetes management which will then obviously improve communication. The concordance model also suggests that unlike in compliance, the focus is on the behaviour and participation of both the patient and the doctor. However, the model poses challenges on the ethical and legal position of professionals when a patient makes an informed decision of not adhering to the treatment as advised since that would predispose the patient to long term risks due to uncontrolled diabetes.

The Health belief model (Rosenstock, 1985) proposes specific variables as being the determinants of health behaviour. This model claims that individuals adopt health promoting behaviour based on a cue to action, perceived vulnerability to the health problem, perceived seriousness of the health problem, the perceived benefits of the treatment proposed or actions advocated and the perceived costs of adopting the treatment or action.

A survey using the Health Belief Model to study compliance levels among chronic diabetics in relation to specific aspects of their medical regimen (insulin administration, diet, management of hypoglycaemia, foot care and urine testing) revealed that those who perceived diabetes to be serious responded to the cues that were suggested for action and were more compliant (Bloom et al., 1980).

Findings from another study on health beliefs, compliance and glycaemic control also interestingly revealed that perceived severity was the health belief that accounted for most of the variance in compliance (Harris et al., 1985). The Health Belief model contains a motivational or incentive component and a set of related beliefs. The model reinforces that it is reward oriented and that individuals are likely to follow health practices if they have an incentive or motivation towards their health along with the following beliefs (Hjelm et al., 1998).

A meta ethnography on the synthesis of qualitative research on lay experiences of diabetes and diabetes care revealed the following findings in relation to varying degrees of compliance (Campbella et al., 2003).

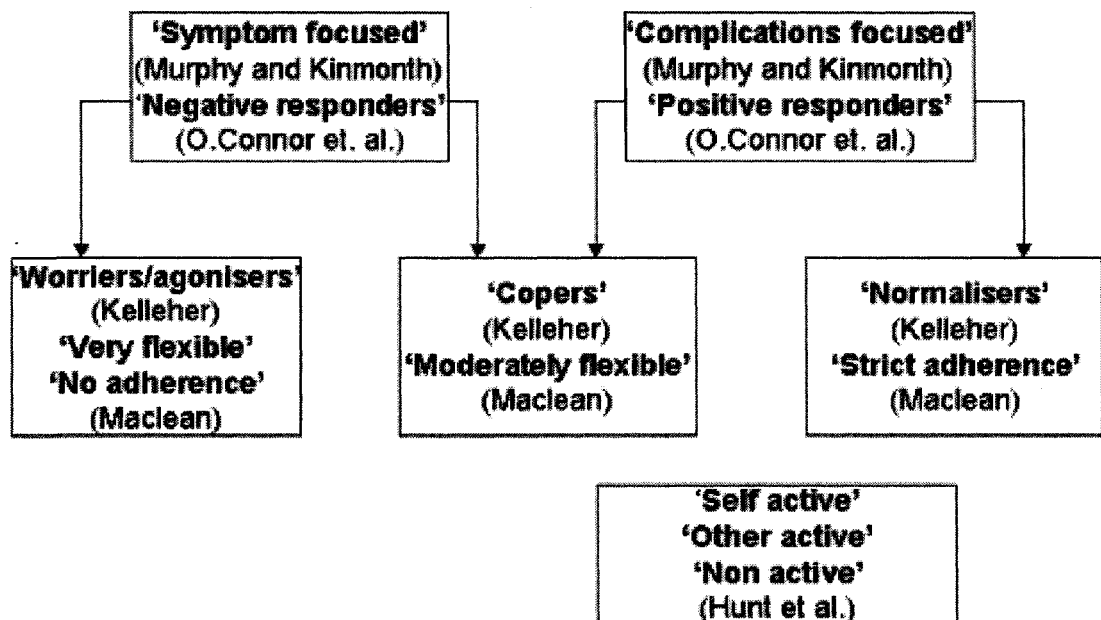


Fig 2. Synthesis of categories of response to diabetes (Bradley et al., 1994)

A study by Kelleher organized peoples' responses to diabetes as 'copers' who altered the timing or dosage of their medication and diet to preserve their work and social life, 'normalisers' who accepted their diabetes and made very minimal alterations and regarded themselves to be healthy and played down the seriousness of their diabetes and 'worriers / agonisers' who considered themselves unhealthy and worried about

their diabetes. They didn't have the confidence to make the changes required or accept it as part of their life. The 'worriers / agonisers' were also found to be women (Kelleher, 1988).

Maclean's study on peoples' responses to their diabetes diet along a continuum reports responses ranging from 'strict adherence' to 'moderately flexible', 'very flexible' and 'no adherence' at the other. Those who strictly adhered did so because of their recent diagnosis of diabetes or to prevent long term complications. Individuals who were 'moderately flexible' allowed themselves occasional indulgences. The 'very flexible' people ate without any restriction and monitored their blood glucose levels and maintained it with self regulation of medications. The 'no adherence' group at the end of the continuum described themselves as 'miserably obsessed with food' (Maclean, 1991).

Two groups of people have been described as 'those avoiding short term complications' and 'those avoiding long term complications' with Type 2 diabetes following a study to describe the meaning which diabetes held for this group of patients (Murphy et al., 1995). Three categories of participants were reported when the relationship between lay theories of diabetes causation and peoples' self care behavior was examined. They were described as 'self active' (personally active in their treatment), 'other active' (someone else was taking responsibility for treatment) and 'non active' (no one was pursuing treatment). They also reported that those who attributed events / heredity to be the cause for their diabetes were 'other active' or 'non active' (Hunt et al., 1998).

There is a disjunction between 'expert' and 'lay' risk assessments. Individuals' explanations of an illness are usually based on a compilation of their own cultural beliefs and the information that they have had from the biomedical health care team about an illness (Gillibrand et al., 2001). In the lay theory model of illness causation, the aetiology of an illness is placed within the individual, the natural world, the social world or the supernatural world. The causes are mainly placed within the individual or natural world in the western cultures as against the non western cultures where people

commonly believe that illness is related to social or supernatural causes. Beliefs regarding health and illness influence health care seeking patterns among individuals (Bhopal et al., 1999).

Health professionals also need to consider that factors such as age, literacy skills, language, socio cultural factors, gender, educational background, social support available, the individual's role within the family, the family dynamics and motivation can greatly influence one's ability to learn new behaviour that is required in the management of diabetes.

Socio cultural and religious practices among South Asians – Implications towards diabetes management

Dietary Practices

Dietary practices vary within the Asian community depending on their religious beliefs and country of origin. Dietary studies of three different groups of Asians (Muslims, Sikhs and Hindus) in Nottingham and Derby revealed significant differences in the consumption of dietary fibre and saturated fat (Hawthorne et al., 1993). Fat in the form of ghee is often consumed and is also considered to provide a 'richer' taste to the food. Ghee is considered pure and is used in several ceremonies because of its religious symbolism. Many sweet and savoury snacks are often deep fried. In this context, it would be difficult for Asians to understand the need to reduce fat and use polyunsaturated oils instead (Greenhalgh et al., 1998). Being plump or a larger body size is perceived as an indicator of better health (Hawthorne et al., 1993) and as a sign of affluence. Hospitality is greatly valued and practised among South Asians.

Family and kinship ties are very strong and family members visit each other as often as possible. It is customary that food which usually consists of sweets, deep fried snacks and sugared coffee or tea is offered as a welcoming gesture. It is a social etiquette and is important to be seen to receive hospitality with good grace. It is

considered offensive to refuse to eat and hence patients often find it quite uncomfortable to mention their dietary restrictions to their hosts. Following a healthy diet as required may be difficult for people with diabetes, if they are surrounded by people who enjoy eating and also expect the individual with diabetes to eat without these restrictions.

Despite their cultural traditions with dietary practices there is evidence to show that Asian diabetic patients are concerned about their diet. The London Ethnic Health Project found that 11% of all telephone enquiries were about diabetes and diet (Samanta et al., 1986). Most Asian diabetic patients feel that they are not given appropriate dietary advice for the food they eat (Hawthorne, 1990).

Travel

The concept of 'extended family' is still much valued and is widely practiced in the Asian community (Hawthorne et al., 1993). Asians travel back to their country of origin for prolonged periods of time because of the close links with their families back home. This is particularly common among the older South Asians. In addition, South Asians from the Muslim background travel to Mecca on pilgrimage as their religious duty which supercedes everything else. These practices cause disruption to diabetic management, monitoring of glycaemic control and screening for diabetes related risks.

It is reported that while South Asians are in their homeland, they believe that the higher temperature and associated sweating reduce their blood glucose levels and hence tend to feel better. Subsequently, they discontinue their medications while they are abroad (Aslam et al., 1986). The focus of education therefore needs to be on information related to travel, the need to continue their medication and arrangements for follow up while they are away for extended periods of time.

Religion

The religious groups among the South Asians primarily consist of Hindus, Sikhs and Muslims. Religion does not seem to have a major influence on the diabetic control among the Hindus and Sikhs. Customs and practices within Hinduism are closely interwoven. “Karma” is a law of behaviour where people believe that the actions of their past life determine their current circumstances including their health. Therefore, despite their ability to understand the biological causes of their illness, for most Asian Hindus, health is related to the inter relationship between the body, mind and spirit and their “Karma”. The elderly tend to focus spiritually in preparing their soul for life after death based on their religious beliefs (Hjelm et al., 1998).

The South Asian Muslims consider going on a pilgrimage to Mecca (Hajj) and fasting during Ramadan as religious duties with a very high priority. All Muslims are expected to go on Hajj at least once in their life time and so the older people aspire to fulfil this religious duty despite their ill health or poor diabetic control. Visiting the mosque to pray on Fridays in particular is regarded as an essential feature of their religious duty (Kannayiram et al., 2006).

Ramadan which is an annual festival involves fasting for a period of forty days during the day light hours. Muslims are permitted to have two big meals each day during Ramadan, one before sun rise and one after sunset which could have implications on calorie intake and drug compliance. In a study on compliance and drug therapy in fasting Moslem patients, it was observed that 37 out of 81 patients changed their dosage patterns during Ramadan and 35 of them missed their doses altogether. The carbohydrate intake was substantially increased by 36 patients during that time (Hawthorne et al., 1993). Friday being their holy day, the attendance at diabetic clinics held on Fridays or access to any health care facility tends to be poor.

Health care beliefs

Health beliefs and health care philosophies between the South Asians and the European population are very different (Kannayiram et al., 2006). Within the Asian culture, family members and friends are expected to make hospital visits, participate in performing personal care and spend time with the individual who is unwell. It is perceived as a very valuable opportunity and a social obligation to provide support to the individual and the family (Fuller, 1995; Husband, 1995). Health issues are seen as a family concern rather than the individual's concern in some non European cultures (Oettingen, 1995). Cultural differences influence different perceptions and self-efficacy which in turn influences involvement in self-care. Individuals who have grown up in a society based on 'dependent collectivism' with hierarchical relationships and class differences learn to obey authorities, which leads to less independent behaviour, infrequent independent thinking, lowered self-efficacy and higher reliance on others (Hjelm et al., 1998). This also has a strong bearing on the external locus of control in people from these cultural backgrounds.

South Asians hailing from such societies, tend to perceive that somebody or something else, the physician or medication for example take control of their disease and in their minds they transfer the responsibility of managing their disease to the health care professional rather than recognise it as their own responsibility (Kannayiram et al., 2006). This in turn significantly impacts upon the locus of control that an individual has towards his or her disease management. Patients expect the doctors to know all the answers and make all the decisions. They usually assume a passive role by answering questions asked rather than actively participate in their health care decisions. They would prefer to be told what to do and may perceive the physician to be incompetent if he didn't take charge completely (Wray, 2003).

Perceptions on Ageing

Perceptions on ageing vary between different groups of people and are influenced by cultural differences across an individual's life span (Wray, 2003). It also depends on the timing of major life course events such as marriage, childbirth, familial responsibilities and arrival of grand children into the family. It is essential that one understands the cultural differences in ageing because it emphasizes the importance of cultural values and priorities throughout the life course especially in women whose perceptions tend to depend on their position and role expectations. This also explains the relationship between ethnic life course inequalities and the resultant disempowerment as one becomes older. It is common among South Asian men and women to regard themselves older at an earlier age than Europeans probably because of their shorter life expectancy and major life course events (e.g. marriage and having children) which occur at an earlier age in comparison to other ethnic groups (Desai, 1990).

With ageing, an individual often yearns for familiarity with a strong desire to have family members or people from within the same culture around them. Familiar food, people and surroundings assume greater significance (Ahmad et al., 1996). Despite having lived as an immigrant for several years and the impact of the acculturation process that is inherent in immigration, many traditions and practices that are central to one's culture and beliefs remain alive in the community especially if the social network is strong. Beliefs such as this probably predispose the individual to frequent travel to one's country of origin for extended periods of time and thus interfere with the diabetes management. The extended family system with strong parental authority still remains central to many South Asians. In many Asian families, important decisions including decisions regarding health care are made jointly rather than by the individual alone. Each family is a strong corporate group and the members are expected to live cooperatively together under the same roof sharing common assets and property (Anwar, 1979). The relationships are kinship based with reciprocal relationships of 'moral, social and financial obligations' and are an important source of identity and support (Husain et al., 2006).

In a study on self – harm in British South Asian women report that women were demanded to behave in a less westernised fashion by their husbands and their mothers in law interfered with the way the women chose to live their lives. The Asian families are also critical about the behaviour of women. Approval of ‘good’ behaviour is expected to be in accordance with the community’s norms and expectations. The women in the study have also expressed their reservations against a community grapevine that intruded into their personal space and privacy leading to a sense of isolation. The sense of isolation was further compounded with their inability to speak English. This may have implications for women in terms of accessing information or services for management of their diabetes (Chew-Graham et al., 2002).

The traditional cultural barriers prevent South Asian women from accessing services. (Desai, 1990) reports in his study on psychological distress and self – harm among South Asian women that services weren’t accessed since the service providers were usually white with a lack of understanding of the Asian culture. They perceived the solutions offered to their problems were ‘simplistic and yet unrealistic’ since they were often not in line with their cultural norms or social expectations.

Older Asian immigrants are often financially dependent on their children. In addition to the challenges of living in a culturally different society, they also need to cope with language barriers, changes in life style, different social expectations and role reversal. When an individual’s expectations are not met in the country that he or she has migrated to, stressful adjustments can often become necessary. Individuals also tend to believe that if they had remained in their own countries, they would have experienced ageing more as a normal part of life in a familiar environment (Pidgeon et al., 1992).

Communication and Language barriers

Communication difficulties such as language barriers, issues related to the use of interpreters and illiteracy were reported in a study done on healthcare professional's perceptions of beliefs about health and illness in migrants with diabetes (Wright, 1983). Patients from the South Asian background have a relative lack of fluency in English and prefer to choose general practitioners who speak appropriate Asian languages for their healthcare and use children or other relatives as interpreters during consultation (Helman, 2000).

Risk perception

One of the definitions of risk is the probability of an adverse event (Lupton, 1993). The synonyms of risk are danger, hazard, peril, threat and probability. Thus, risk is implicitly negative and is associated with loss of some sort to the individual concerned. The physical consequences of hazards, such as deaths, injuries or harm, are concrete facts. However, assessment and perception of risk are subjective. They are based upon individual attitudes, socio cultural beliefs, gender or age and are dependent upon human judgement and individual life experiences. Risk is also an 'ideologically loaded' concept (Pidgeon et al., 1992). Risk perception has been defined as 'involving people's beliefs, attitudes, judgments and feelings as well as the wider cultural and social dispositions they adopt towards hazards and their benefits' (Gifford, 1986; National Research Council, 1996). Risk has different meanings to different groups of people and all risks need to be understood within the larger social, cultural and economic context (World Health Organisation, 2002b). Similarly, perceptions of risks to health are embedded within different economic, social and cultural environments (Douglas et al., 1982). Risks can best be understood as a social construct within particular historical and cultural contexts and within groups and institutions and not only at the individual level since individuals are social beings (Nelkin, 1989; Ogden, 1995).

Therefore, risks should not be treated independently and separately from the complex social, cultural, economic and political circumstances in which people experience them (Douglas, 1992). Different groups of people appear to identify different risks, as well as different attributes, depending on the form of social organization and the wider political culture to which they belong (World Health Organisation, 2002b). Risk perceptions and their significance can vary between developing and developed countries, as well as with such variables as sex, age, gender, faith and cultural groups, urban and rural areas, and geographical location. Most of the risk perception models were however developed in the industrialised countries where people have considerably more personal autonomy, better access to health care and information and the scope for making choices for better health (Park et al., 2001).

Both the cognitive and the affective domains are used by individuals to perceive risks. The cognitive dimension refers to how individuals assess their own likelihood of coming to harm, whereas the affective dimension refers to the uncertainty, concern, worry, or anxiety that people feel about risks that are likely to come their way (Cook, 2006). Risk perception is influenced by cultural influences, peer pressure, membership of a religious community and socio economic status. Perception of risk is also context specific.

Generally, people tend to underestimate risks associated with voluntary behaviours of their choice as against risks that are likely to be present from external sources. For instance, a smoker may not consider his smoking behaviour to be risky but on the other hand be very concerned about a natural disaster such as the Tsunami that is likely to occur in his living environment. Individuals also tend to rate their personal risks less than that of an average person and therefore would like to be in control of the kind of risks they take but would interpret that the behaviours of their choice are less risky (Tate et al., 2003). Individual differences with risk experience also contribute towards intensifying perceptions of risk.

The magnitude of risk as perceived by the individual depends upon whether the risk is perceived to be voluntary, familiar, amenable to modification and associated with

obvious benefits and impacts (Tate et al., 2003). It is still not very clear cut, if changes in health risk perceptions will facilitate positive health behaviours. However, understanding the socio cultural factors that impact health risk perception can provide useful avenues for designing mitigation, health promotion and risk prevention strategies (Adams et al., 2001).

The timing of the risk also influences how it is perceived. Complications that are imminent and are likely to be permanent have a greater impact than those that are transient and occur later on. If the risk is possible to be treated, then the perception of its severity is also minimised (Lima et al., 2005). With the continued experience of threatening situations, individuals develop strategies to minimise risks in order to cope with the situation. Constant exposure to a threat or frequent contact with it may lead to becoming habituated to its presence with the possibility of accepting a hazard and its negative consequences as a normal phenomenon. This has been found to be particularly true for voluntary risks or those with less-visible consequences (Barnett et al., 2001). In this process, individuals may become desensitized when the frequency of contact with the threat is high with not very significant consequences. These have significant implications with the way South Asians with Type 2 Diabetes perceive risks since most long term risks related to diabetes are asymptomatic, transient and develop gradually over a period of time.

“Desensitization” may also be used as a coping strategy in situations where admitting to the risk would impose serious negative consequences such as perceived loss of control or identity. Voluntary risks are also usually associated with perceived or actual benefits as against involuntary risks where the individual has had no control over their occurrence in the past or with their prevention in their future (Crisp et al., 1995). Therefore, in individuals with Type 2 Diabetes risk perceptions are likely to be influenced by low visibility of risks and the idea that individuals have that they have no control over preventing it from happening.

Locus of control and risk perception

The locus of control in an individual can be both internal and external. In relation to chronic illness, those individuals with an external locus of control are more likely to depend on the health care system to intervene with their illness. In contrast, those with an internal locus of control are more likely to be confident in managing their illness and will work towards achieving greater levels of self efficacy.

Individuals with an internal locus of control who perceive that their actions could minimise the potential threat or harm tend to be more aware of the various health conditions as against individuals whose locus of control is external. The latter tend to believe that they are helpless however hard they try since they perceive that the forces are external to them over which they have no control. They also believe that despite their actions, consequences of risks cannot be minimised and hence take things as they come or leave it to their destiny. Negative outcomes of any sort are often attributed to fate and there is an acceptance of powerlessness over the situation when the locus of control is external (Gustafson, 1998).

Gender and risk perception

Risk research spans a wide range of disciplines such as technology and economics into social and behavioural sciences. Psychologists argues that risk perceptions have subjective dimensions and the anthropologists believe that risk is socially and culturally constructed (Gustafson, 1998). Gender research has secured prominence among most researchers in recent times and there is a growing appreciation that gender makes a difference to risk perception.

Risk perception has often been studied using the psychometric approach with questionnaires and statistical methods. The limitation with this approach has been that the emphasis in these studies has usually been on differences between risks rather than on differences among those perceiving the risks. These studies have often revealed predominantly male experiences. Perceived seriousness of different risks also had

very minimal gender based differences (Flynn et al., 1994) when measured using psychometric, quantitative approaches. Quantitative studies with the explicit objective of finding gender differences also confirmed that women's and men's relative ranking of risks didn't vary significantly (Fischer et al., 1991).

Qualitative studies on the other hand have been able to elicit marked gender differences of risk perception. (Gustafson, 1998) found that women were found to be more inclined towards perceiving risks as threats to their families or close relatives and the risks that they identified frequently were related to accidents, health and death. Gender differences also involve variations in the way risks are framed. The same risks may mean different things with varied interpretations for both men and women. Women's risk perception is also related to their social roles and everyday activities. Women largely function as care providers and home makers within family and community settings and this may be associated with concern about health and safety issues (Stern et al., 1993).

Men on the other hand focussed more on risks related to their working lives, unemployment and economic issues since their role expectation is to be "providers" which is described as "father effects" by (Flynn et al., 1994).

Gender and ethnic differences in risk perception are also likely to be influenced by socio-political factors such as power, status and trust. In a study on gender, race and perception of environmental health risks among the white population, it was obvious that women perceived risks as higher than men (Flynn et al., 1994). On subsequent analysis, it was found that the men who were less concerned about the risks that were being investigated had significantly better education, higher income and expressed higher levels of trust in institutions and authorities and were also politically more conservative. Thus, gender differences in the perception of risk seem to highlight not just the gender differences in activities and social roles but also unequal power relations and different levels of trust people place in authorities and institutions. This also opens up the possibilities for risk perception to be influenced by differentiation based on race and social classes to which the individuals belong (Gustafson, 1998).

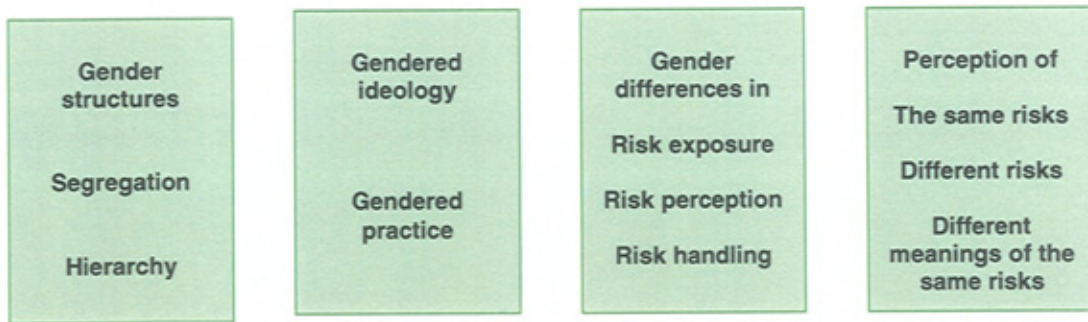


Fig 3. Relationship between gender and risk perception (Gustafson, 1998)

In summary, gender differences in risk perception can be categorised as women and men expressing different levels of concern about the same risks, perceiving different risks and attribute different meanings and interpretation to the same risk (Gustafson, 1998).

Gender differences in risk perception are social processes and not just 'natural' or biological. Gender relations are also power relations which are not accidental but systematic. They represent the underlying gender structures. The influences of gender structures on men and women are moderated by structural factors such as class and ethnicity. However, they are also responsible for creating systematic differences such as segregation (female and male) and hierarchy (unequal power relations, male dominance and female subservience). All these have significant bearing on how individuals perceive risks of various sorts.

Gender structures are mediated and maintained through gendered ideology and gendered practice. Ideology refers to people's values, belief systems, norms and opinions. Practice refers to what people actually do in a given context. Quite often there is interplay between the two, given the understanding that an individual's behaviour or practice is driven by his or her beliefs and values.

Gendered ideology also defines role and social expectations. The role expectations are described by gender role theory and then in turn reinterpreted through various socializing agents such as the family, school, peer groups, mass media and religious

groups. This has however been criticised as denying the elements of individual agency and use of free will. Gendered ideology and structure seem to be socially driven with hierarchical dimensions (Gustafson, 1998).

In this context, gendered ideology, practice and gender structures are all connected and influence risk perceptions. Therefore, the exposure to risk, perception of risk and the handling of risk could all be different for both women and men. Risk and gender research have the potential not only to bring to light what gender has to say about risk but also about what risk has to teach us about gender (Kasperson et al., 2001).

Social Amplification of risk

The theory of social amplification (Meacham, 2004) of risk suggests that risk perception can be amplified based on the risk interaction with psychological, social, institutional and cultural processes and this in turn shapes risk behaviour.

Consequently, the behavioural responses are then not just confined to direct impact on the individual's health or his immediate environment but will also have social and economic effects depending on the amplification of risk.

The extent to which a risk is attenuated sometimes depends on social and political pressures. The attenuation of risk may have direct implications for acceptance of the risk and its management. Consequently, depending on the risk amplification and the impact that it brings, an individual is either likely to take the risk seriously or not (Clarke, 2000). Thus, it is distinctly clear that risk construction is not straightforward and objective but instead is bound by socio cultural and several other factors (Jezewski et al., 2002).

UK South Asians and Diabetes related risks

South Asians in the UK (migrants from Bangladesh, India and Pakistan) (Great Britain. Census, 2001) comprise approximately 4% of the population of the United Kingdom (Riste et al., 2001). The prevalence of Type 2 Diabetes has been escalating

among the South Asians in many parts of the world including the United Kingdom (Abate et al., 2001). The prevalence of diabetes is two to three-fold higher in SA compared with their white counterparts (Philips, 1995). This is believed to be due to an excess of insulin resistance, determined by environmental and/or genetic factors (Bhopal et al., 1999).

The South Asian population is heterogeneous (Hawthorne et al., 1993) and has marked language, religious, social and cultural differences not only between South Asians and Europeans, (Balarajan, 1996) but also between different groups of South Asians. The risk factor profile that predisposes South Asians with diabetes to coronary heart disease is very varied and dependent on their socio cultural and religious practices and health beliefs. Tools such as Framingham, Finland Cardiovascular Risk (FINRISK) and Systematic Coronary Risk Evaluation (SCORE) grossly underestimate risk in South Asians when used to predict cardiovascular risk (Bhopal et al., 2005). Therefore, the interventions towards risk prevention driven by findings from research within the western populations may result in inadequate treatment of diabetes for South Asians (Barnett et al., 2006).

Factors such as increased insulin resistance due to abdominal obesity, genetic predisposition, sedentary lifestyle, reduced physical activity, raised blood pressure and smoking contribute to the cardio vascular risk factor profile among South Asians. All seventeen studies that were reviewed in relation to physical activity and fitness among UK South Asians reported lower levels of physical activity when compared to the general population (Fischbacher et al., 2004).

Findings from The United Kingdom Prospective Diabetes Study (UKPDS), the largest clinical research study of diabetes ever conducted (Turner et al., 1998) reveal that increased concentrations of low density lipoproteins, decreased concentrations of high density lipoprotein, hyperglycaemia, hypertension and smoking are significant risk factors for coronary heart disease in patients with Type 2 diabetes. The study has provided conclusive evidence that the life threatening complications (risks) of Type 2 diabetes (non insulin dependent diabetes) can be significantly reduced by appropriate

treatment. The results from this large trial have irrefutably shown that the emphasis must be on achieving optimal blood pressure and blood glucose levels from the time of diagnosis. Treatment of Type 2 diabetes, a progressive condition with serious long term risks must aim at achieving and maintaining long term near-normal blood glucose and blood pressure levels. Lifestyle changes such as dietary modification and exercises alone were reported as being insufficient to maintain target blood glucose levels in most people with Type 2 diabetes. Therefore, combinations of therapies inclusive of insulin are required over time to maintain glycaemic control because of the progressive nature of the disease (Great Britain. Diabetes UK, 2006c). The UKPDS recommends that blood pressure and the HbA1c levels are maintained at 130 / 80 mm Hg and 6.5% or below respectively. Findings from this study have led to a paradigm shift in the management of Type 2 diabetes with risk prevention as the core of diabetic management. Initial dietary advice on fat and calorie restriction along with high fibre intake impact upon weight and blood glucose control.

It is recommended that all patients with Type 2 diabetes must have their glycaemic control reviewed at 2 – 6 monthly intervals and monitoring aspects such as blood pressure, lipid profile, urinary albumin, renal function, retinal screening and foot examination are done every 6 to 12 months towards screening for diabetes related risks and risk prevention (Great Britain. National Institute for Health and Clinical Excellence, 2002).

Minority ethnic groups such as the South Asians are increasingly susceptible to diabetes related risks due to their dietary habits (increased intake of fat) and low levels of physical activity. Statins (Cholesterol lowering agents) are now widely recommended to prevent cardiovascular risk particularly for those of South Asian descent following the publication of the Heart Protection Study (Heart Protection Study Collaborative Group et al., 2003) and the Collaborative Atorvastatin Diabetes Study (CARDS) (Colhoun et al., 2004).

They also have the unenviable position of having the highest death rates of coronary heart disease in the United Kingdom (Bhopal et al., 1999), with Bangladeshis being

particularly disadvantaged (Mather et al., 1985). The rates of ischaemic heart disease are 30 – 40% higher amongst South Asian men than men in the general population in the UK (Great Britain. Health Survey for England, 2001) with a 50% higher mortality rate than that for the total population of England and Wales (Chaturvedi et al., 1996). The increased predisposition to coronary heart disease is seen even in the second generation immigrants (Shaukat et al., 1994) with increased mortality in the younger immigrants (Balarajan, 1996).

The increase in the incidence of coronary heart disease is associated with the increased risk of Type 2 diabetes, which develops about 10 years earlier in the South Asians than in Europeans (Mather et al., 1998). Renal complications are also seen commonly (Chowdhury et al., 2002). Many of the risk factors for these complications such as poor glycaemic control, smoking, elevated blood pressure and dyslipidaemia are modifiable. Because of their increased susceptibility to the risks related to diabetes and given the proviso that they are modifiable, early interventions to attenuate this risk are of significant importance in the South Asians with Type 2 Diabetes (Collins et al., 1994; Collins et al., 1990). The incidence of stroke and myocardial infarction can be significantly reduced with optimal control of blood pressure, (Great Britain. Medical Research Council, 1992) particularly in older people (Hawthorne et al., 1993).

Meeting the health needs of any heterogeneous minority ethnic group such as the South Asian population requires sensitivity to their traditions, culture, religious practices and health beliefs. The United Kingdom Asian Diabetic Study (UKADS) (O'Hare et al., 2004) was designed in response to this need and to test the hypothesis that structured, culturally sensitive care for South Asians with Type 2 diabetes can improve cardiovascular risks with cost effective strategies. 361 patients of South Asian origin with Type 2 diabetes and one of the diabetes related risks (hypertension / dyslipidaemia) were randomly allocated to either enhanced or conventional care. Those allocated for enhanced care received additional support from Asian link workers, practice nurses and community diabetes specialist nurses in addition to the treatment protocol. A follow up after one year revealed a significantly greater

reduction in the mean blood pressure (systolic & diastolic) and the cholesterol level and increased compliance with therapy in the enhanced care group.

There are several socio cultural factors linked to the increased prevalence of Type 2 diabetes and coronary heart disease among the South Asian population including lack of diabetes related knowledge, poor use of health resources and a different attitude towards chronic disease (Hawthorne, 2001; Rankin et al., 2001; Vyas et al., 2003). It therefore becomes crucial for practitioners to be sensitive and knowledgeable about the various socio cultural practices and health beliefs in relation to risk perception among South Asians in order to improve access and utilisation of the services for diabetes management.

UK Policies and Practice for Type 2 Diabetes Management

Low socio economic conditions and communication gaps due to language and literacy barriers between South Asians and their care providers have resulted in sub optimal utilisation of health resources increasing their vulnerability to diabetes and its related risks. Diligent management can yield benefits, in terms of fewer complications, upto nine years in the future (The Diabetes Control and Complications Trial Research Group, 1993). Health professionals have since adopted long-term views of risks.

Considering the incidence, prevalence and the magnitude of diabetes related risks in the South Asian population, a number of organisations such as the Department of Health, Diabetes UK, the South Asian Health Foundation and the British heart Foundation have identified objectives and planned strategies to meet with these challenges, the cardiovascular risk in particular. Some of these activities include increasing awareness of diabetes and CHD through greater community-based activities; providing and promoting more culturally specific information for groups at increased risk; greater partnership with relevant community organizations and funding of community and research projects (Barnett et al., 2006).

The National Service Framework (NSF) (Great Britain. Department of Health, 2002) acknowledges the disproportionate burden of diabetes among South Asians and has proposed initiatives to reach communities at greatest risk in an attempt to raise the standards of diabetes care. As recommended by the UKPDS, the NSF advocated strategies to improve blood glucose and blood pressure control in people with diabetes which would in turn reduce the risks of diabetes such as heart attacks, strokes, blindness and renal failure by a third. Targeted foot care was proposed to save hundreds of amputations every year. Detection and management of long term complications is one of the key elements of the NSF with three standards (Standards 10, 11 and 12) set in place exclusively towards this aim (Great Britain. Department of Health, 2002). Strategies such as regular surveillance, implementation of recommended protocols for blood glucose and blood pressure control, monitoring systems of care to ensure timely and appropriate investigations and provision of multi agency support (integrated health and social care) were planned towards reducing the risk of disability and premature death that would result from diabetes.

Early identification of diabetes, psychological and emotional support and education for self care are some of the key priority areas identified towards the implementation of the NSF by the Diabetes UK (Great Britain. Diabetes UK, 2006b). 53 percent of the Primary Care Trusts (PCTs) in England have a programme in place to promote early identification of diabetes considering the relative under diagnosis of diabetes in the general population (Great Britain. Diabetes UK, 2006a). Self-care is the cornerstone of diabetes care as 95 per cent of managing the condition is self-care. The extent to which people can manage their diabetes to reduce the risk of complications is determined by their understanding of the disease.

Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) is the first national structured educational programme that aims at promoting self care for people with Type 2 Diabetes. The provision of structured education to Black and Minority Ethnic (BME) communities is an area of particular interest for many primary care organisations and specialist services. In an attempt to do this, Bangladeshi Initiative for the Prevention of Diabetes (BIPOD), an initiative

with the Bangladeshi community to determine knowledge of diabetes related risk is in progress in order to enhance understanding of factors influencing eating and activity to inform the development of culturally relevant diabetes prevention strategies and to identify training needs in health professionals.

The DESMOND Black and Minority Ethnic (BME) study, aims to build on the DESMOND programme to devise a methodology by which an English language structured education programme can be developed for use with an ethnic and/or cultural minority (Great Britain. Diabetes UK et al., 2005).

The Diabetes, Attitudes, Wishes and Needs (DAWN), was yet another landmark study (Funnell, 2006) that involved a cross sectional international survey in 2001 with the purpose of identifying a broad set of attitudes, wishes and needs among both people with diabetes and their care providers to lay a foundation that would improve diabetes care nationally and internationally. The survey reported very low rates of self management behaviours especially for diet and exercise by both patients and practitioners. The data also reported diabetes related psychosocial problems and barriers that interfered with self management in patients across participants from 13 countries. Even though these problems are universal in diabetes management, the complexities of these issues will be even greater while caring for a diverse and heterogenous population such as the South Asians. A high percentage of care providers (78.8 %) reported that they needed a better understanding of the various ethnic cultures (Peyrot et al., 2005) which highlights the need to build the existing knowledge base on cultural diversities in managing diabetes and equip practitioners to deal with these challenges. This would in turn facilitate the achievement of various standards and targets as proposed by the NSF for diabetes.

Concepts such as self management and concordance which advocate partnership in decision making with risk prevention as the core of diabetes management are difficult propositions for both South Asians with diabetes and their care providers given the socio cultural diversities, language and literacy barriers. The current recommendations by the UKPDS, NSF standards and Guidelines laid out by the National Institute of

Health and Clinical Excellence require regular hospital visits for monitoring and a comprehensive understanding of diabetes by South Asians with diabetes if the proposed targets around risk prevention need to be achieved. These may have serious impediments for South Asians if one were to apply the Theory of Planned Behaviour (Ajzen, 1991) since their behavioural beliefs (attitude toward proposed health behaviour – risk prevention) are influenced by their normative beliefs (socio cultural beliefs and practices) and perceived behavioural control that is mostly external to themselves (external locus of control in relation to risk perception).

From the health care professionals' perspective, issues such as metabolic control, patient education and coping strategies have been emphasized. From the existing evidence base, a lot of emphasis has been placed on medical models of care, which are treatment orientated (Fisher et al., 2002). An ecological model that would approach the issue at different societal levels, from the individual, groups, families, health care professionals and communities to policymakers and encourage the adoption of preventive lifestyle changes by individuals at risk may also be appropriate (Jezewski et al., 2002) especially in long term conditions such as diabetes.

Key Summary

The management of any chronic illness given its complexity includes psychological, social and emotional aspects. In the same light, it is essential that we understand the lifestyle, beliefs, attitudes, and family and social networks of the patients for successful diabetes management (Cohen et al., 1994). Traditional western prescriptive models of diabetes care focus on adherence to a regimen (Greenhalgh et al., 1998). Health care beliefs about Diabetes mellitus vary significantly from those accepted by Western medicine among Bangladeshi immigrants, especially in terms of diet and exercise (Avis et al., 1989). The underlying assumption in the psychological models of health-related behaviour, is that it is important to understand perceived susceptibility (or risk) since it is instrumental in motivating change in behaviour (Glasgow et al., 1999). Since behavioural issues are central to the management of

Diabetes even in the early stages of the disease (Duff, 2003), it becomes essential to understand the various perceptions of risks related to Type 2 Diabetes.

From the extensive literature review that was undertaken for this study, it was apparent that an Explanatory Model (EM) of risk perception in diabetes among South Asians is not available. Explanatory Models usually focus on the individual's explanations of the illness causation, symptoms, severity, and treatment of the illness, and often include lay and biomedical perspectives. Inherent in the study of Explanatory Models is the notion of illness versus disease. Disease is conceptualized as the biomedical view of the patient's complaints interpreted within the framework of the medical model. While considering developing an Explanatory Model of risk perception of an illness it is essential to include the social, cultural, religious values and health beliefs of individuals, the family dynamics and the context that they live in since all these impact upon the way an individual understands and perceives health related risks. Developing Explanatory Models of risk perception from patients will prove to be beneficial for both providers of health care and researchers studying patient-provider interactions (Cohen et al., 1994).

The training programmes for health care professionals emphasise the importance of patient education with a relatively less emphasis on considering the patients' perspectives in designing those programs (Poulton et al., 1986). This can cause serious implications and lack of confidence among health care providers if the goal of patient education is to provide a culturally competent approach. The health care professionals' lack of knowledge about the culture and health beliefs of South Asians can predispose to generalisation and stereotyping. (Koehn et al., 2005) report that the regular medical training and clinical experience in the United Kingdom does not prepare practitioners in any specific way for them to practice medicine among the Asian community. Education on the cultural aspects of ethnic minorities alone may not solve the problems. Lack of awareness regarding the cultural processes among Asians may be a barrier to effective service delivery to people with Type 2 Diabetes.

Conclusion

There seems to be a lack of common understanding of risk as a concept even among professionals. These complexities will be even more exaggerated while providing services for South Asians with diabetes. Health care professionals often debate with issues around patient versus professionals' autonomy around risk taking, risk allowances that are permissible while having the professional responsibility and accountability to ensure client's safety at all times. The other challenges include the extent of professionals' role in providing knowledge and information to patients with diabetes so that they make 'informed choices', measuring the acquisition of knowledge and information, given the complexities with language, literacy, culture, and health beliefs, lack of processes to facilitate the transition from knowledge of risk to practice and maintaining a balance between ensuring patient safety and patient autonomy.

The Explanatory Models related to diabetes, have almost exclusively been conducted in Caucasian females. Significant differences have been revealed in a study conducted by (Larme et al., 1998) on variations in Explanatory Models of diabetes between primarily well-educated, Caucasian, Protestant patients and their health care providers. Communication with patients is affected when health care providers do not understand patients' conceptions of diabetes (Hernandez, 1995). The conventional "adherence paradigm" used by diabetes educators (Duff, 2003) that does not usually take into account the patients' perceptions of an illness and its related risks can become futile and unsuccessful with patients becoming increasingly sceptical of the validity (Campbella et al., 2003) of the health education and information that is purely based on the biomedical model of an illness. This makes it necessary for relationships between patients and health care providers to be based on a deeper understanding of the patients' experiences of living with diabetes.

Research that incorporates perspectives of risk among minority ethnic groups such as the South Asians with diabetes is particularly valuable because of the "centrality of patient voice" (Hjelm et al., 2003). The research findings of this study would also help

to determine the relevance and diversity of cultural considerations in providing health care services especially with the escalating incidence of Type 2 diabetes in this population.

This study will also enable us to understand issues related to patient practitioner variations in risk perception, the health behavior and how South Asians with diabetes actually experience living with the illness, understand and engage with diabetes related risks. There is also a role towards including factors such as healthy lifestyle and its impact on the prevention of non communicable diseases such as diabetes in the development of the nursing curriculum and educating practitioners on the cultural aspects of South Asians which would facilitate optimal utilization of the available resources and effective diabetes management.

CHAPTER: 3

METHODOLOGY AND METHOD

Research Question

Risk perception among older South Asians with Type 2 Diabetes in the United Kingdom.

Aim of the investigation

To develop a conceptual model on risk perception among older South Asians with Type 2 Diabetes in the United Kingdom.

Objectives

- To identify the factors that influence risk perception among older South Asian men and women with Type 2 Diabetes.
- To identify gender variations in the perception of risks related to Type 2 Diabetes.
- To identify patient/practitioner variations in risk perception.

Central to answering a research question is to develop an appropriate research design. This chapter proposes to demonstrate the philosophical relevance and position of the research design chosen and explain its theoretical and methodological perspectives. The study used the grounded theory research methodology, with its theoretical foundations drawn from symbolic interactionism. The research question, “How do older South Asian men and women with Type 2 Diabetes perceive risks related to their diabetes?” does not fit into the positivistic paradigm of research that focuses on theory testing, establishing cause – effect relationships, predicting and controlling variables (Polit et al., 2003). An inductive, qualitative approach is more relevant and

appropriate and was therefore chosen for this study. The qualitative approach enables the exploration and discovery of themes that are important to the population under study. It facilitates the discovery of motives or values and beliefs behind those themes leading to an understanding of a phenomenon of not just what happens but why it happens.

Research in nursing is conducted within both the quantitative and qualitative paradigms. The quantitative paradigm seeks to measure, analyse, generalise, generate and disseminate knowledge towards practical application. This is also known as positivism and it has its legitimate position in inquiry through experiments and surveys within nursing research. In the positivist approach, one assumes that an objective reality exists independent of human observation since nature is believed to be basically ordered and regular (Polit et al., 2003). The research emphasis in the positivist paradigm is focused on understanding the causes of a natural phenomenon. With objectivity being the hallmark in this approach, every attempt possible is made to hold personal beliefs and biases in check while studying any phenomenon.

In recent years, researchers have been challenged to explain any phenomenon under investigation especially within health care settings. There is an increasing demand to answer challenging questions which involve lived experiences and subjective interpretation especially in clinical settings. Evidence based care is the buzz word in health care today and its experts claim that it will enhance informed use of evidence, optimal use of limited resources, and the empowerment of both practitioners and patients (Sandelowski, 2004).

The philosophy of nursing emphasises individualised, holistic and comprehensive patient care in addition to the acquisition of knowledge and development of skills. This is very congruent with qualitative approaches which focus on experiences of people and emphasise the uniqueness of individuals (Parahoo, 1997). Qualitative research has been recognized as a vehicle to gather important insights into the culture, practices, and discourses of health and illness, and for developing knowledge about meanings not amenable to quantification (Denzin et al., 2000; Gergen et al., 2000)

Caring for diabetes involves understanding essential social phenomena such as family relationships, food preferences and beliefs about health and illness (Anderson et al., 1998b). This indicates that it would be useful to employ qualitative methods to gain information in depth especially if the area of research is relatively unexplored and the research question is loosely defined or open ended (Helman, 1991). The implication of this for this study manifests in two ways. Firstly, in relation to diabetes, there has been an increasing recognition of the need for in depth exploration of the health beliefs of people with diabetes that influence their ability to make these lifestyle alterations (Anderson et al., 1998b). It is therefore, an appropriate way to study this field in which optimal management of diabetes involves significant lifestyle changes for patients, which is often difficult to achieve and maintain.

Secondly, patients and professionals have varied understanding of illness and the associated risks. Practitioners tend to describe risk commonly as the probability of occurrence of a related adverse event associated with non compliance to medical advice or if precautions are not taken as required. Patients' understanding of risk can be influenced by their past experiences, spirituality, interaction with family members, peers and other social groups. The individual's society and culture, including references to beliefs and systems of meaning also facilitate this process. It has been reported that people often tend to over estimate small risks and make their choices either to take a risk or avoid it depending on whether the outcomes are described as gains or losses (Reyna, 2004).

Risk perception involves beliefs, attitudes, the autonomy that an individual has, the ability to make choices, the social environment and culture. It is influenced by an individual's thoughts, beliefs and value systems which tend to be socially driven. Cognition, on the contrary refers to higher mental functions such as thought, memory and the ability to use judgment or make appropriate decisions. Thus, risk perception is more closely related to social psychology than cognitive psychology (Sjoberg, 2000) and would therefore be better understood using a qualitative approach.

Three factors need to be considered when selecting a research approach (Field et al., 1985). Firstly, the nature of the phenomenon to be described must be considered. In this study, the purpose was to increase the understanding of risk perception by older South Asians with Type 2 Diabetes in the United Kingdom.

The second factor is the maturity of the concept – that is the extent to which the concept is known and understood must be evaluated. There have been qualitative approaches used to study lived experiences, gender variations and meanings people attributed to their diabetes (Kelleher, 1988; Koch, 2000; Koch et al., 1999). The area of risk perception in relation to Type 2 diabetes among the South Asians is relatively unexplored. It is challenging to assess risk perception since the construction of risk is varied depending upon the social dynamics and the social processes involved. Risks to health have been largely defined from the scientific perspective until recently. Lay people tend to form their own ideas and understanding of health related risks through personal experience, social expectations, and priorities in their lives which may vary from the medical model of risk. Patients with diabetes tend to discuss symptoms along with their personal and social difficulties associated with their diabetes. Professionals are inclined towards discussing the related physiology and metabolism and often display limited understanding of patient's wider psycho social needs in caring for their diabetes (Cohen et al., 1994).

The third factor identified by (Field et al., 1985) is constraints arising from the subjects or setting. In this study, recruitment of participants for the study, using bilingual interpreters to address issues with language during interviews were some of the issues that needed to be dealt with. The details of how these issues were addressed to improve rigour are discussed later on in the chapter.

Grounded Theory

Grounded theory is a qualitative research approach that enables exploration of social processes that occur within human interactions. It has therefore been considered as an important research method to study nursing phenomena. Its origins began more as a systematic method of qualitative research than as a philosophy (Polit et al., 2003).

A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory stand in reciprocal relationship with each other (Strauss et al., 1990).

Grounded theory is a strategy for both doing research and analyzing the data collected. It seeks to generate a theory which relates to the phenomenon being studied. The theory thus generated is 'grounded' in data collected during the investigation particularly in the actions, interactions and social processes of the participants involved in the study. Thus, it is highly relevant to be used in nursing research and requires the constant comparison of collected and coded data, hypothesis generation, use of the literature as data and collection of additional data to verify or reject hypotheses which is very characteristic of grounded theory (Stern et al., 1982).

This method has the following salient features (Robson, 2002b). It

- Provides explicit procedures for theory generation.
- Offers a flexible, systematic and coordinated strategy for conducting research.
- Provides explicit procedures for data analysis.
- Is very valuable in applied areas of research especially where the theoretical approach to be chosen is not very clear cut.

Grounded theory is process oriented, providing description of stages over time (Morse, 2002). It allows the development of theories that are meaningful to the research participants which is an essential outcome of any investigation. Grounded theory 'allows this theory to emerge from the data, so that it does not lose touch with

its empirical referent' (Bryman, 1988). This study intended to assess the factors that influenced risk perception related to Type 2 diabetes among older South Asians. It was therefore essential that the theory on risk perception emerged from the data which would then significantly add to the existing knowledge base. Grounded theory provides a framework for the qualitative researcher to cope with the unstructured complexity of social reality and so renders it manageable (Bryman, 1988). The concept of risk perception is very complex and an unwieldy social reality that would be hard to investigate without a framework and the advantage of theoretical sampling that grounded theory is able to provide. The research question in grounded theory is formulated in such a way that it gives researcher the flexibility and freedom to explore the phenomenon in depth (Backman et al., 1999).

Grounded theory, which is a research methodology rather than a theory itself was developed from the theory of symbolic interactionism (Glaser et al., 1967). Grounded theory research aims to develop substantive or formal theory and thus serves as a vehicle for explaining social processes (Chenitz et al., 1986b; Robrecht, 1995); Grounded Theory is a highly systematic research approach for the collection and analysis of qualitative data for the purpose of generating explanatory theory that furthers the understanding of social and psychological phenomena (Chenitz et al., 1986a)

The reliance of nursing research on other disciplines has resulted predominantly in deductive approaches with theory testing rather than theory generation (Chenitz et al., 1986a). Nursing as a profession and practice discipline deals with several concepts and phenomena including 'risk' and hence needs to generate its own theories within the context of patients which reflect the values and meanings of the people involved.

Thus, the present study is of an inductive nature and used the grounded theory which is qualitative in its approach. Qualitative inquiry has the potential to describe the phenomenon of interest in all its complexity and ambiguity with appropriate consideration of context and attention to the meaning of events and experiences for participants (Zyzanski et al., 1992) very clearly mirrors the purpose of this study.

The other possible interpretive models that were available to use were Phenomenology and Ethnography. Phenomenology aims to produce a description of a phenomenon of everyday experience in order to understand its essential structure and focuses on the subjective experience of the individual studied. It also emphasises the importance of reflexivity – an awareness of the ways in which the researcher as an individual with a particular social identity or background can impact upon the research process (Robson, 2002a). Bracketing where all pre existing knowledge, understanding and preconceptions of a phenomenon are suspended prior to commencing the research has been described to be a significant barrier with the phenomenological approach (Annells, 1999). Phenomenology was not chosen as the interpretive model for this study for the following reasons:

- The researcher being a nurse from the South Asian background could have imposed several opportunities for bias and bracketing would have been a constraint. The researcher's familiarity with South Asian beliefs, culture and values could have impacted upon the way the interviews were structured because of the assumptions and preconceived ideas about this population. It may have resulted in a loss of spontaneity and less inquisitiveness on the part of the researcher because of the presuppositions that are difficult to eliminate. The researcher coming from a nursing background and often in the position of "telling" people what to do as a practitioner would have caused conflicts between the "researcher" role and the "confidant" role (Wilde, 1992) that demands that personal and professional knowledge of the researcher be set aside while interacting with research participants.
- The study also aimed to understand the various factors that influence risk perception among older South Asian men and women with Type 2 Diabetes and not just the individual's lived experiences with Diabetes.

Ethnography aims to provide a description and interpretation of the culture and social structure of a social group. To be able to do this, people are studied for a long period of time in their own natural environment (Robson, 2002a). Culture is one of the many

factors that influence risk perception. Ethnography also requires the researcher to be able to study the participants in their natural setting for extended periods of time and participate in what goes on in their environment. With this study being a PhD research project, there were constraints with time and funding. The primary focus of the study however was not to study the culture and social structure of South Asians but rather understand the factors influencing the perception of risk in relation to their diabetes. Hence this wasn't chosen as the interpretive model for this study.

Several variations of Grounded theory have evolved since Glaser and Strauss initially described it. The methodological development depends largely on the researcher's epistemological and ontological beliefs. The work of Glaser has been described as the *traditional Grounded theory* and that of Strauss and Corbin is named as the *evolved Grounded Theory* (Mills et al., 2006) .

The traditional form of Grounded theory requires the researcher to adopt an inductive approach and enter the field of inquiry with no preconceived ideas in order to facilitate the theory to emerge from the data. Generation of provisional hypotheses are permitted only after the initial data collection and the hypotheses are subjected to verification with subsequent data collection (McCann et al., 2003a). The theory thus generated can be tested deductively. This stance of Glaser is more inclined towards a positivistic position.

On the contrary, Strauss and Corbin advocate the reconstruction of a theory that is richer and more reflective of the context in which the participants are situated and therefore insist that their approach is interpretive in nature (Strauss et al., 1994).

The following table clearly summarises the main epistemological and methodological differences between Glaser's and Strauss and Corbin's approaches to Grounded theory (McCann et al., 2003b).

Table: 1 Differences between Glaser's and Strauss and Corbin's approaches to Grounded theory

Features	Traditional Grounded Theory (Glaser)	Evolved Grounded Theory (Strauss & Corbin)
Epistemology	Critical realist ontology; More positivistic	Social constructivist and less positivistic
Researcher's role	Independent	Dialectic and active
Focus of inquiry	Main emphasis on symbols, interactions and context; Emphasis on socially constructed world of participants.	Emphasis on structural, contextual, symbolic and interactional influences; Emphasis on describing cultural scene and socially constructed world of participants.
Literature Review	Preliminary review is discouraged; Main purpose is to support the emerging theory.	Preliminary review to enhance theoretical sensitivity; Main purpose is to support the emerging theory.
Research Problem	Emerges during the study	Personal experience, suggestion by others, literature; Also emerges during the study.
Data collection and analysis	Guided by participants and Socially constructed reality.	Rules and procedures; Paradigm model to provide structure.

For the purpose of this study (Development of a conceptual model on risk perception in older South Asians with Type 2 diabetes), it would not have been feasible to adapt the traditional form of grounded theory that requires the researcher to enter the field of enquiry with no preconceived ideas considering the South Asian origin and the professional (nursing) background of the researcher. The evolved Grounded theory was found to be more relevant and feasible to answer the research aims of this study. This form of Grounded Theory is also not very rigidly prescriptive and hence promotes researcher flexibility. Guidelines such as the use of literature, coding, memo writing, theoretical sampling, constant comparative analysis, measure of rigor and theoretical sensitivity that are used to describe the steps of the research process as recommended by the evolved Grounded Theory were adapted to suit the purposes of the study as described later on in the methods section of this chapter.

Symbolic Interactionism

Symbolic interactionism is one of the interpretivist perspectives in research and, according to (Schwandt, 1994b) is the theory and approach for the study of individuals' social and psychological action/interaction 'in search of portraying and understanding the process of meaning making.'

Symbolic Interactionism has its origins from the pioneering work of George Herbert Mead, a social psychologist in the early 1900s. It was influenced by the pragmatic view that all human beings go through a constant process of adaptation in their social world that is forever changing and that the change is made possible because of the mind that is able to contemplate over a situation and direct the change that is required in order to adapt as required. Symbolic interactionism was taken further as a sociological theory and research approach by Herbert Blumer. Symbolic interactionism fundamentally operates within the three following premises (Blumer, 1969).

- The first premise is that human beings act toward things on the basis of the **meanings** that the things have for them.

- The second premise is that the meaning of such things is derived from the **social interaction that an individual has with his fellow beings**.
- The third premise is that these **meanings are handled in and modified through an interpretative process** used by the individual in dealing with the things he encounters.

Symbolic interactionism is one of the interpretive perspectives in research. It is a theory and approach to study individuals' social and psychological interactions as they try to understand and attribute meaning to various phenomena in their lives. The goal of this tradition is to understand 'the complex world of lived experience from the point of view of those who live it' (Schwandt, 1994a).

The position of Symbolic interactionism is that the meanings that things have for human beings are central in their own right. Symbolic interactionism views meaning as arising in the process of interaction between people. The meaning an individual attributes to any thing is derived from the ways in which other individuals act towards him / her with regard to the situation or thing. Social life is formed, maintained and changed by the basic meaning attached to it by people who interact within the social system. Social life and objects become significant and have an identity when they are assigned meanings (Robson, 2002a). Thus, Symbolic interactionism sees meanings as social products, as creations that are formed in and through the defining activities of people and their interactions.

Symbolic interactionism is based on a number of basic ideas, or root images which refer to human groups or societies, social interactions, objects, human action and the interconnection of the lines of action. Fundamentally, human groups or society exist in action and hence must be seen in terms of action. Culture and social structure are two major concepts within any given society. Culture is clearly derived from what people do whether defined as custom, tradition, norms, values or rules. Similarly, social structure in any of its aspects, as represented by such terms as social position, status, role, authority and prestige refers to relationships derived from how people act toward each other in the given social context.

A cardinal principle of Symbolic interactionism is that any empirically oriented scheme of human society, however derived must respect the fact that in the first and last instances, human society consists of people engaging in action. To be empirically valid, the scheme must be consistent with the nature of the social action of human beings (Blumer, 1969). Thus for symbolic interactionists, ‘meaning’ is the key element in understanding human behaviour, interactions and social processes. It therefore becomes mandatory for the inquirer to grasp and understand the meanings that are attributed and experienced by the participants in the given social context in order to understand the social process (Jeon, 2004).

Individuals tend to base their actions on the meanings that they hold for that particular situation. These meanings are attributed through social interaction and experiences shared with other individuals and human beings as ‘social actors’ attach meanings to situations, people or themselves through a process of interpretation (Taylor et al., 1984).

Within the context of this research, the three principles of symbolic interactionism can be interpreted as follows:

Risk perception in South Asians with Type 2 Diabetes is influenced by the meaning that these individuals attribute to their Diabetes.

An example from this study as stated below explains that the meaning attributed by Sa’ood to his Diabetes is that it is a trial from God associated with rewards in later life; He also believes that the rewards are in proportion to the trials that one undergoes. Risks (trials) related to diabetes were perceived in this light.

“So, I think depending on my faith, predestination these are tests and trials from God. So, He tests you in one way or the other. So, this is one way, He’s testing me perhaps. There is a reward you know, reserved for you for the life

after death. So, actually, more and more trials and tribulations that you go through, more reward is there...” (Sa’ood)

Risk perception is based on the social interaction that the South Asians have with other individuals.

The examples (from this study) below clearly articulate that the individuals take their risks related to diabetes seriously because of their social interaction or past experience with other individuals with a similar illness.

“When I listen to other people and you see them because there is one lad younger than me with Diabetes, he said that it has affected his feet. That gave me a shock.”(Daanaa)

“Risks are there because if you take excess of sugars and if you don’t take care, risk comes and you have to get rid of your life? (Death) also. Risks are more because I’ve seen; practically I have seen my friends. They lose parts of them with amputation or something. So, one should be very careful.” (Baahir)

Meanings are handled in, and modified through, an interpretive process.

The example below clearly illustrates the meaning Maahir attributes to Diabetes and interprets it as being responsible for his loss of identity and independence.

“They’re worried. Everyone is worried. My wife’s worried, my childrens are worried, you know. I’ve, I’ve been active, you know. I mean, I’ve done all this wall papering and painting myself, you know. I’ve done everything. Even fixed my rooms, you know, maintain my own car most of the time, you know all these things is dead stop now. I call this guy now to do my one room, you know. I could have done it myself. You know, I think my family is a bit, too protective. They don’t want me to exhaust myself, I think, you know. I was upstairs last night, trying to get a scrape over, take a paper out and they jumped on me saying, “Go down. Sit down. Don’t do.” This is bad, that.

You see this, mostly I've done it myself. (Points to the garden). All the paving. It was alright. Put this fence up a few year ago, you know. You know, I was a very handy man but now I've only got half a body left, you know. No use." (Maahir)

The central aim of this study was to understand risk perception among older South Asians with Type 2 Diabetes and develop a conceptual model. To understand risk perception in this population, it was crucial to identify the meanings they attributed to diabetes and its related risks, the social interaction, values and beliefs that influence their risk perception and the way in which risks were interpreted and handled. Thus, Symbolic Interactionism was the most ideal philosophical and theoretical approach to demonstrate risk perception among South Asians with Type 2 diabetes.

With the ever changing society globally and the changes being so rapid, Symbolic Interactionism seems to be an essential way of helping people remain connected with identity as part of a group. The symbolic interactionist perspective offers an opportunity for South Asians with Type 2 Diabetes, their health care professionals and the ethnic Health Development Workers to be able to attribute their meaning in relation to risk perception. It also empowers the South Asians with Type 2 Diabetes to actively engage in this process rather than be passive recipients of the diabetic services that are offered.

Symbolic interactionism is based on the assumptions that communication requires the use of shared symbols; construction of self and identity are through human interaction which also enables the creation of society. Using the perspectives of Symbolic interactionism, this study would facilitate the understanding of the various meanings South Asians attribute to risk perception in relation to their Diabetes. This in turn would enable the health professionals to understand the South Asians' perspectives on risk perception and promote the provision of culturally sensitive services. It therefore becomes very crucial that there is communication and shared understanding among health care professionals (service providers) of what influences risk perception in South Asians with Type 2 Diabetes to make their services culturally more relevant and effective.

Method

Research design

A qualitative research design using grounded theory with its theoretical foundations drawn from Symbolic Interactionism was used.

Ethical Approval

The proposal was subjected to the following ethical scrutiny and approval was obtained.

- School of Health, Community and Education Studies (HCES) Research Ethics Sub Committee of the Northumbria University.
- The participant's GP was informed in writing regarding their participation in the study to ensure that they were not repeatedly approached for research purposes (Appendix 8).
- Local Research Ethics Committee of Newcastle and North Tyneside (Appendix 9).
- Research and Development department of the Newcastle PCT (Appendix 10).
- Caldecott Guardian of the Newcastle PCT to access the medical notes of the participants (Appendix 11).

Sample Selection

A purposive selection using inclusion and exclusion criteria was used. There are several types of purposive sampling such as intensity sampling and maximum variation sampling as described below which make the data more 'information rich' (Denzin et al., 1994).

Inclusion Criteria

- South Asian men and women who are above 50 years of age. The average life expectancy being 63 years in the South Asian population (The World Bank Group, 2004). South Asians also consider themselves to be ‘old’ in terms of fulfilment of life’s responsibilities (marriage, childbirth, provision of financial security for the family and education for sons / marriage of their daughters). These life events and responsibilities are usually completed by around fifty years of age and hence individuals above fifty years of age were chosen for this study.
- Diagnosed to have Type 2 diabetes of at least 2 years duration with the presence or absence of diabetes related risks (e.g.) cardiovascular problems.
- Health Development Workers, Physicians, DNSs and Dietitian involved in the Diabetes care of South Asian men and women in Newcastle upon Tyne.

Exclusion Criteria

- Those who did not wish to consent to participate in the study.

For this study, the significant informants were considered to be the Ethnic Health Development Workers, health professionals (physicians, nurse specialists and dietitians) who work with South Asians with Type 2 Diabetes and older men and women of South Asian origin with Type 2 Diabetes. They were purposively chosen since they were likely to have sufficient knowledge and experience related to the research question (Risk perception in older South Asian men and women with Type 2 Diabetes).

Intensity Sampling: Aims to select participants who are experts in the topic being researched. To achieve this, two focus group interviews were conducted with the Ethnic Health Development Workers (EHDW) from the Health Development Service of the Newcastle Primary Care Trust (PCT) and seven individual interviews were conducted with physicians, Diabetes Nurse Specialists (DNS) and a dietitian who work among South Asians with Type 2 diabetes. Twenty older South Asians with Type 2 diabetes were also interviewed.

Maximum Variation Sampling: Aims to select a heterogeneous sample of participants based on their commonality of experience with the topic being researched. In this study, a maximum variation sampling of older South Asians with Type 2 Diabetes was chosen to explore the phenomenon of risk perception related to their diabetes. To ensure that the data was 'rich', a heterogeneous sample of participants based on their commonality of experience with the topic being researched was done within this group as given below. The commonality of their experience was their South Asian origin living in the UK and that all of them had Type 2 diabetes. Heterogeneity was ensured by selecting participants from Bangladesh, India and Pakistan with their commonality being the South Asian background and as people having Type 2 diabetes. Men (nine) and women (eleven) from these groups were included to ensure maximum heterogeneity.

Theoretical sampling (Within Purposive Sampling)

Sampling methods and the sample size impact upon the scientific rigour of any research in terms of its validity and reliability (Morse, 1991). The sampling methods used in the quantitative paradigm are not applicable to qualitative approaches (Marshall, 1996). Values, beliefs, attitudes and life experiences form the core of any qualitative study. These are not normally distributed within the study population. Therefore, every participant's experience is unique and valid; an appropriate sample size for a qualitative study is one that adequately answers the research question. The number of participants required becomes self evident as the study progresses until data

saturation where new categories, themes or explanations cease to emerge from the data.

Sampling in grounded theory is one of the key determinants of the quality of the theory generated. Theoretical sampling is the usual approach to sample selection. The selection of sample is guided by the phenomenon being studied rather than the need to be representative of the study population. The sample size in grounded theory is determined by the data generated and their analysis which occur simultaneously. Interviews are the primary source of data in grounded theory. Observation and analysis of documents could be the other sources of data.

In grounded theory, the sampling process is initiated by interviewing significant informants (purposively chosen) who are knowledgeable and experienced with the phenomenon being explored, who can provide relevant sources of data and who are able to articulate their experiences. A significant informant is “someone who has the knowledge and the experience the researcher requires, has the ability to reflect, is articulate, has the time to be interviewed and is willing to participate in the study” (Morse, 1991). This type of purposive sampling within grounded theory is known as theoretical sampling (Robson, 2002b).

Theoretical sampling, is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses the data and decides what data to collect next and where to find them, in order to develop the theory as it emerges (Glaser et al., 1967). It is used as the study progresses and helps to choose the kind of questions to be asked, exploration of themes that emerge with subsequent interviews and where to generate such data from and thus becomes an integral part of the constant comparative method of data collection and analysis which is the other key component of grounded theory. Thus, in grounded theory research, there is a process of purposive sampling which is then superceded by theoretical sampling as the data gathered channels the direction for further sampling (Cutcliffe, 2000) and is driven by the emerging theory.

In this study, the participants were chosen purposively (Health care professionals working among South Asians with diabetes and older South Asians with Type 2 diabetes). Theoretical sampling was used as the interviews progressed and were analysed. Information from the initial interviews guided subsequent interviews especially when themes such as ‘patient tourism’, ‘barriers’, and ‘creation of safety nets’ emerged from the data.

Another methodological issue with sampling in grounded theory research is the choice to be made between a wide and diverse and a narrow and focused sample. A wide and diverse sample (Lincoln et al., 1985) is recommended since that would ensure extensive data and cover a wide range of information. Maximum variation sampling has also been advocated since that would make the data more ‘information rich’ and valuable. Maximum variation sampling within theoretical sampling is best achieved by choosing the subsequent samples only after the previous set of data has been taped and analysed. The first person interviewed often functions as the ‘gate keeper’ and sets the stage for further data collection. This also poses the risk of limiting the scope of a complete understanding of the phenomenon being studied if the first participant has a limited understanding or inability to articulate the related experiences (Cutcliffe, 2000). This was overcome by doing the focus group interview as the first interview which provided insight into several issues (socio cultural and religious practices, priorities, understanding of diabetes etc) that needed exploration around risk perception in Diabetes among the South Asian population. This also minimised the risk of limiting the scope of a complete understanding of the risk perception phenomenon since it had the advantage of multiple participants who provided rich and in – depth information from their experiences.

This study aimed to explore risk perception among older South Asians with Type 2 diabetes, gender variations in risk perception and patient practitioner variations. A focus group interview was done initially with the ethnic Health Development Workers (from the South Asian background). The focus group consisted of both men and women representing all the three South Asian communities (Bangladesh, India & Pakistan) who had wide experience with providing services for South Asians with

Type 2 diabetes. The interview facilitated the process of theoretical sampling and provided valuable insight into issues such as peoples' understanding of diabetes, perceived severity, response to diabetes related risks, barriers to providing services, priorities, gender variations, the importance of religion and spirituality and family dynamics within the South Asian culture.

The data from the focus group interview influenced the questions asked in subsequent interviews with health care professionals and the older South Asians with Type 2 diabetes – for example, the belief among some South Asians that their diabetes existed only while they were in the UK and the issue of frequent travel to the country of origin for extended periods of time that affected the continuity of care and follow up of diabetes management especially among older South Asian women were explored in depth with both the practitioners and the South Asians with diabetes.

Theoretical sampling pertains only to conceptual and theoretical development. It helps to obtain data to explicate categories. It involves starting with the data at hand, constructing tentative ideas about the data and then examining these ideas through further empirical inquiry. Theoretical sampling can be used both in the early stages of research to develop preliminary categories in the later stages of research to demonstrate links among categories (Charmaz, 2006). It helps to identify gaps in the analysis and directs further data collection in order to saturate categories. It is the quality of data that is paramount rather than the frequency with which a pattern appears in order to achieve theoretical saturation. Saturation is not seeing the same pattern over and over again. It is the conceptualisation of comparisons of these incidents which yield different properties of the pattern, until no new properties of the pattern emerge. This yields conceptual density that when integrated into hypotheses make up the body of the generated grounded theory with theoretical completeness (Glaser, 2001).

Theoretical sampling within the purposive sampling was done at various levels as the interviews progressed in order to make the data 'information rich'. A focus group interview was done initially with the Ethnic Health Development Workers to identify

the key issues from their experience of working with South Asians with Type 2 Diabetes in relation to risk perception which helped to develop the interview with the health professionals. The focus group interview and the interviews with the health professionals enabled identification of specific issues and questions from their perspective that needed to be addressed. These in turn shaped the individual interviews with the older men and women with Type 2 Diabetes as described earlier on in this chapter. Constant comparison of data from within the focus group and interviews with health professionals led to the choosing of participants from Pakistan and Bangladesh in order to explore specific issues pertaining to risk perception among them. The interviews fed back into each other as outlined in the figure below.

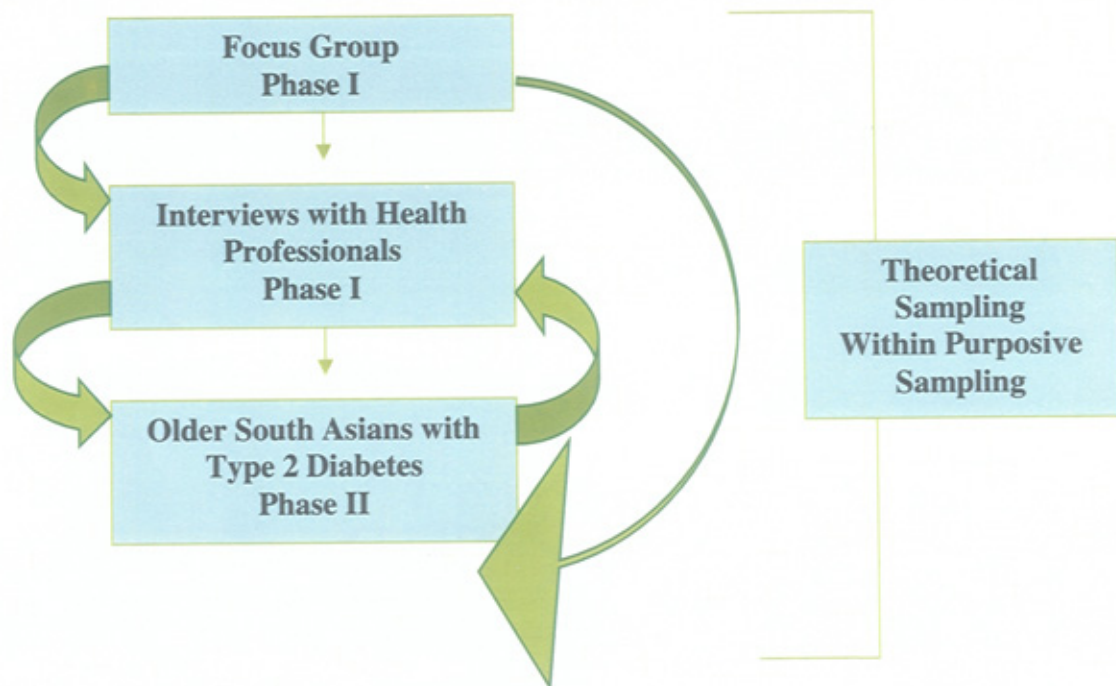


Fig 4. – Flowchart on Theoretical Sampling

For example, data from the interviews with health professionals revealed that there were language barriers with providing information around risk awareness and this was explored in depth during the interviews with the South Asians. Provision of information in different languages alone didn't seem to suffice to address issues around the language barrier since there were literacy issues. Practitioners also reported

that there was a gap in understanding the socio cultural and religious practices that influenced risk perception in this population. To explore both these issues further, attempts were made to interview South Asian practitioners. The one interview that was held with a South Asian practitioner also confirmed that despite his knowledge and familiarity with the socio cultural and religious factors that influenced risk perception, he still faced the same language barriers in providing information on risk awareness due to literacy barriers and the wide diversity within the South Asian culture.

SEQUENCE OF THEORETICAL SAMPLING

Research Participants	March 2004	April 2004	May 2004	June 2004	Dec 2004	Jan 2005	Feb 2005
Health Care Professionals	3	3	1				
South Asian Men	1	4	2	1	1	Nil	Nil
South Asian Women	Nil	2	5	2	Nil	1	1



Fig 5. – Sequence of Theoretical Sampling

Data from one set of interviews led to the theoretical sampling in the subsequent interviews as shown above. Specific issues in relation to gender, culture, religion, understanding of diabetes and factors influencing risk perception were explored using theoretical sampling. For instance, participants who had a family member as a health care professional seemed to have a strong internal locus of control that influenced the way they perceived risks. This was initially observed from analysing the data from interviewing a male participant in the month of March. It was subsequently explored with two other male participants in the month of April and May. Later on, women participants who had a health care professional as their family member were identified

and interviewed to explore this further in June 2004 and Jan 2005. Thus, the findings from one set of interviews led to in depth exploration of issues identified in subsequent interviews using theoretical sampling until data saturation was achieved.

Table 2: Sampling profile of the twenty older South Asian people with Type 2 Diabetes

Participant Pseudonym	Age (Years)	Gender	Country of origin	Duration of stay in the UK (Years)	Languages spoken	Duration of diabetes (Years)	Co morbidities (Diabetes related risks)
Galina	63	F	India	>20	Punjabi	6	Dyslipidaemia
Hadarah	62	F	India	>20	Bilingual	10	Nephropathy & Dyslipidaemia
Chandana	54	F	Bangladesh	<5	Sylheti	9	Hypertension
Maasma	50	F	Pakistan	>20	Urdu	5	Hypertension
Ila	44	F	Bangladesh	>10	Sylheti	8	Multiple
Saabira	73	F	India	>20	Bilingual	7	Multiple
Adya	69	F	Pakistan	>20	Punjabi	12	Dyslipidaemia Hypertension
Padma	75	F	India	>20	Bilingual	24	None
Rabia	58	F	Bangladesh	>15	Sylheti	18	Retinopathy & Neuropathy
Madhur	54	F	Bangladesh	>20	Bilingual	9	Hypertension
Haala	57	F	Pakistan	>20	Urdu	7	Dyslipidaemia
Anil	55	M	Pakistan	>20	Bilingual	2	Retinopathy
Kiran	81	M	India	>20	Bilingual	8	Neuropathy & Dyslipidaemia
Baahir	65	M	India	<5	Bilingual	2	None
Abhaya	68	M	India	>20	Punjabi	6	Hypertension & Stroke
Saadya	74	M	India	>20	Bilingual	5	Dyslipidaemia
Daanaa	64	M	Pakistan	>20	Bilingual	31	Erectile Dysfunction
Baqeer	65	M	Bangladesh	>20	Sylheti	1.5	Coronary Artery Disease
Sa'ood	65	M	Pakistan	>20	Bilingual	9	Coronary Artery Disease & Dyslipidaemia
Maahir	60	M	Pakistan	>20	Bilingual	5	Stroke

It is interesting to note from the above table that 18 out of the twenty South Asians had diabetes related risks.

Recruitment of research participants

Negotiation for access

Contacts were made initially with a Nurse Practitioner, the Service Facilitator of the Health Development Service and the Newcastle Diabetes Centre. Links were also made with the South Asian communities through social networks and community based non religious organisations in Newcastle with the help of the Service Facilitator from the Health Development Service (HDS). In order for the researcher to become familiar with the service availability and provision for people with diabetes an application was made with success for the researcher to be an observer at the Newcastle Diabetes centre for a year from February 2004.

The Health Development Service of the Newcastle PCT works in line with the Trust's Primary Care Strategy to address the health needs in relation to diabetes, heart disease and women's health issues among Minority Ethnic Communities in Newcastle upon Tyne. The Health Development Service works proactively with individuals and groups from the South Asian community and provides support, information and advice in their first language. It works in partnership with the local community, health and local authority agencies in promoting and delivering services as recommended by the Standards 1, 2, and 3 of the National Service Framework (NSF) for diabetes among the minority ethnic groups within the PCT (Great Britain. Department of Health, 2002). Trained, bilingual ethnic health development workers work alongside Primary Health Care Teams, Community Health Services and Community Organisations to deliver the service, seeing people at home, in doctors' surgeries and in community groups and events.

The Newcastle Diabetes centre of the Newcastle PCT is a tertiary care centre set up in 1997 with the philosophy of providing high quality service with equal access for all patients with diabetes in the city. This internationally renowned centre provides a comprehensive range of services through a multidisciplinary team which consists of consultant diabetologists, specialist nurses, dietitians, retinal screeners and podiatrists.

Ethnic Health Development Workers (EHDWs)

They are part of the Health Development Service in Newcastle who were contacted through the Service Facilitator and briefed about the project. With their consent, two focus group interviews were conducted with them since the group interaction would produce valuable data and insights that would not be as accessible without the interaction found in a group (Morgan, 1988) and would also have the advantage of dealing with complex issues (Basch, 1987) such as risk perception in diabetes among older South Asians.

Health Care Professionals

One physician, two DNSs and a dietitian involved in the care of South Asians with Type 2 Diabetes were contacted through the Newcastle Diabetes Centre where the researcher had obtained a visitor observer's status since February 2004. The researcher met them individually to explain about the project and disseminate information prior to obtaining informed consent and recruiting them for the project. Two General Practitioners (GP) and a Nurse Practitioner involved in diabetes care were identified from other areas in Newcastle where South Asians live and were contacted personally and recruited after their informed consent. A total of three physicians, three nurse specialists and a dietitian were interviewed.

South Asian People with Type 2 Diabetes

Issues with recruiting South Asian women as research participants have been reported by (McAvoy et al., 1988). Representations were sought from both English and non English speaking South Asians. Gender and ethnic matching were used to ensure social acceptance and for the interpreters to have the ability and competence to conduct the interviews in the participants' first language among the non English speaking participants.

To address issues such as difficulty with accessing participants and obtaining their consent to be interviewed that were anticipated, attempts were made to recruit participants through the EHDWs, DNSs and the Diabetes clinic at the Newcastle Diabetes centre. Only one of the three participants contacted through a Diabetes Nurse Specialist consented to be interviewed. Two of them had withdrawn after signing the informed consent (Appendix 2) with the Diabetes Nurse Specialist. On follow up over the telephone by the researcher, they requested to be withdrawn since they were not interested and had changed their mind. Five of them whom the researcher had contacted personally through the Diabetes clinic declined to consent when followed up. When asked if they had any particular reason for not wanting to participate, they responded saying that they had changed their minds and that there was no other specific reason.

In an attempt to increase awareness in the community and to maximize the response rate, links were made with the South Asian communities through social networks and community based non religious organisations. Similar to the findings by (Rait et al., 2000) the response was encouraging from those participants who met the researcher through informal talks at the community centres.

Recruitment of participants through the EHDWs could have caused a selection bias since they also had the role of service providers. However, with using purposive sampling, meeting the EHDWs individually on three occasions to explain the purpose of the study and reinforcing the fact that it wasn't an evaluation of the service provided and the provision of informed consent prior to being interviewed helped minimise the bias. Participants for this study were recruited purposively through the Ethnic Health Development Workers, Diabetes Nurse Specialists and the links made with South Asian social networks as demonstrated in Figure 6.

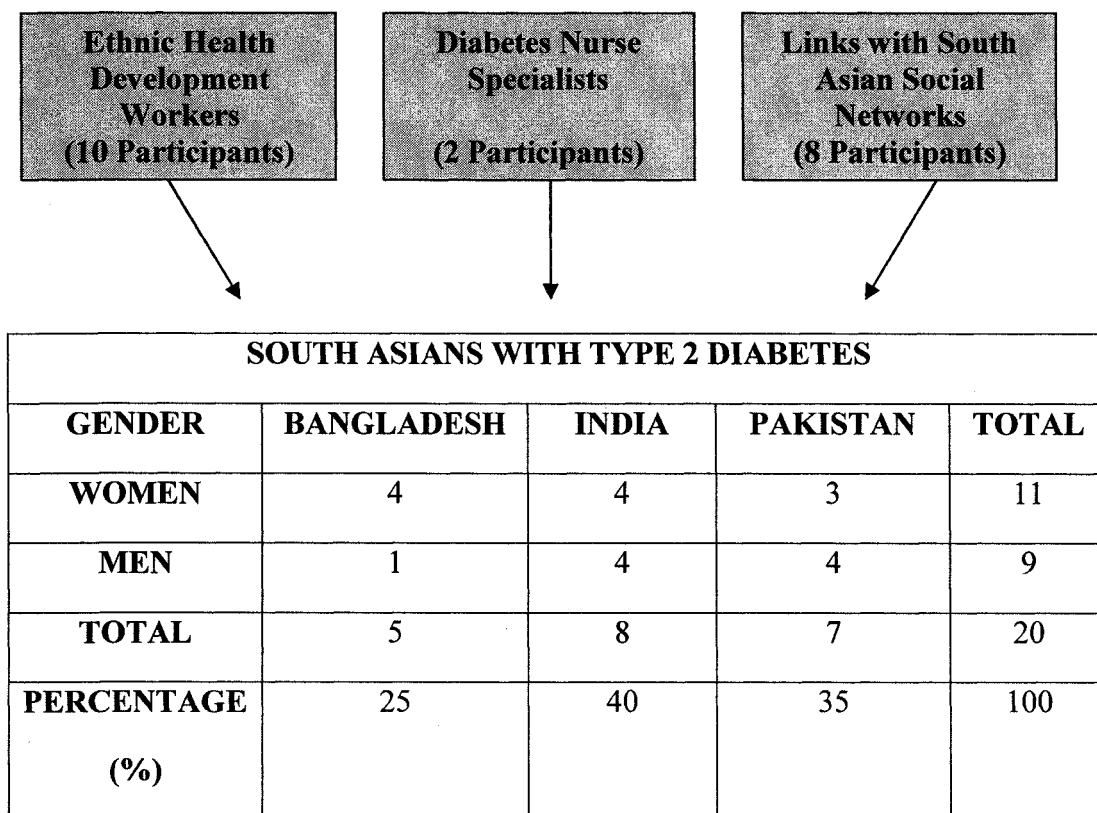


Fig 6. - Recruitment of Participants

Generation of data

Data Collection

The data collection was done in two phases.

Phase I: The first phase involved collection of data from the service providers (Health professionals and Ethnic Health Development Workers). Both the groups have the valuable experience of working with the South Asian Community and data gathered from them contributed to the overall richness and quality of information gathered. A focus group interview was conducted with the EHDWs to elicit data about their experiences in relation to risk perception among the older South Asians with Type 2 diabetes. Individual interviews were conducted with the health care professionals to collect data and enable the researcher to understand the health services available to

people with Type 2 Diabetes and their experiences as service providers in relation to risk perception and risk management among older South Asian men and women with Type 2 diabetes. This was also to enable the researcher to ask the appropriate research questions in the next phase using theoretical sampling.

Focus Group Interviews

The use of focus group as a method of data collection in qualitative research is becoming increasingly popular. They enable collection of in depth information in a relatively short space of time (Twinn, 1998). One strong limitation with the focus group interviews is that there is heavy reliance and dependence on the skills of the moderator in order to ensure that the voice of all the members is heard (Krueger, 1988) . In this study, the focus group consisted of seven members and since the researcher had interacted with all of them on three occasions to orient them regarding the purposes of the study and the interview process, there was no difficulty faced in identifying their voices on tape. The researcher had sufficient experience in leading group discussions gained from her professional background. The three visits made to the Health Development Service to discuss the purpose of the study prior to the interviews also enhanced rapport and familiarity with the members which made the hour and a half long interview 'information rich'. Data from the first focus group was very instrumental in designing the subsequent interviews – Some of the issues that emerged were 'Religion and risk perception', 'Patient tourism' and 'Communication barriers' and there was further exploration of these issues in detail using theoretical sampling of questions asked in the subsequent interviews.

A second focus group interview was done with the Health Development Workers at the end of Phase 2 to discuss specific issues in relation to language barriers and to share their experiences with interpretation for this study.

Phase 2: The second phase involved individual interviews with older men and women from the South Asian background with Type 2 diabetes. Data was gathered using individual interviews.

Conducting the interviews

Interviews are particularly valuable in seeking to understand how people make sense of the situations they are in and identify issues that are important to them. An interview guide with well planned open ended questions and ready probes increase the confidence of a novice researcher. The guide needs to preferably have initial open ended questions (General), intermediate questions and ending questions (Charmaz, 2006). To elicit rich data, the questions need to be open ended and overlapping in order to facilitate going back to something that needs more information.

The interviews were semi structured and a few broad areas for discussion were identified. Prompt sheets for use by the interviewer were developed (Appendices 5 & 6). Past research papers, relevant literature, and the researcher's own knowledge were synthesised to provide topics relevant to risk perception in diabetes among health care professionals & older South Asians.

The following broad areas were identified for inclusion in the prompt sheet for interviews with older South Asians

- **Health in general**
- **Understanding and management of diabetes**
- **Impact of diabetes**
- **Risks around diabetes**

Each area contained a number of subsidiary questions. The participants did not necessarily talk about the topics in the order in which they were printed on the prompt sheet and therefore, use of the prompt sheet had to be flexible. This meant that the researcher had to be alert to those issues which had already been discussed and those which had yet to be mentioned. Familiarity was rapidly gained with the topic areas and reference to the prompt sheet was reduced as the interviews progressed. Given the complexities around the concept of risk, challenges with language barriers and the use of interpreters, it was actually difficult to maintain a broad perspective of the

interview whilst simultaneously giving the participant, the utmost concentration in order to maintain a flow of conversation and ensure all areas were covered. Every possible effort was made to make the study as robust and rigorous as possible despite the various methodological challenges as outlined later on in the chapter.

Data from the medical notes

Data in relation to their glycaemic control was collected from the participants' medical notes (Appendix 5). Approval for this was obtained from the Caldecott Guardian of the Newcastle PCT and had the participant's consent. Duration of diabetes, regularity with attending hospital appointments, co morbidities (diabetes related risks), HbA1C levels over the last three visits, health services accessed and treatment for diabetes were some of the data that were collected. Only seventeen notes were accessible and relevant data was gathered from them. The three other notes were not accessible (since the participants attended the Diabetes centre only for screening during annual reviews while the management of their diabetes was looked after by their GPs) even though the participants had consented for the researcher to go through their medical notes. Data from the medical notes was not collected prior to the interviews to guide the interviews because of the ethical issue involved with obtaining the participant's consent and as a result could not inform the interviews. The notes were only looked at in retrospect after the participant had consented to participate in the study. Findings from this set of data interestingly revealed that it was women who mostly travelled back to their country of origin for extended periods of time, missing hospital appointments and had consistently poor glycaemic control as described in Table 5 which confirmed the data from interviews with the health care professionals as this being a major issue with older women particularly from Bangladesh.

Methodological issues

Rigor was ensured by identifying the methodological issues as outlined below and addressing them to the best extent that was possible. The role of validity, reliability and generalizability in qualitative research has been heavily debated over the years.

Expectations to use the same language and quality criteria in qualitative research as in quantitative research, and the need to 'prove' that an 'unbiased' approach has been used stems from a desire for intellectual and scientific acceptance by the academic community (Tobin et al., 2004). The essential test of validity of a finding in the rationalistic or positivist paradigm is not feasible when a flexible design involving people and human interaction is used. The tendency is to discuss philosophical and technical issues in the same context and this aggravates the difficulties in establishing the relationship between the naturalistic and rationalistic paradigms (Tobin et al., 2004). 'Philosophical issues relate to questions of epistemology...technical issues bespeak the consideration of the superiority or appropriateness of methods of research in relation to one another' (Bryman, 2002). Despite its long history and the undeniable contribution of qualitative research, there have been criticisms that qualitative methods are not rigorous and are subjective (Denzin et al., 2000b).

Qualitative researchers strive for clarity of purpose and rigour in qualitative methodologies. Trustworthiness which is central to qualitative research needs to be demonstrated through credibility, transferability, dependability, confirmability, peer debriefing, audit trail, member checks and triangulation (Tobin et al., 2004).

Goodness (Arminio et al., 2002) is another recommended application of rigour to strengthen qualitative research. It is represented as a means of locating trustworthiness and authenticity which allows the interpretive researchers to shift from the empirical analytical expectations. It is also an integral part of the entire research process and must thus be reflected throughout the entire study.

The six following elements have been recommended as essential for goodness to be reflected in an interpretive study (Arminio et al., 2002).

- Foundation (epistemology and theory) – this provides the philosophical stance and gives context to and informs the study.
- Approach (methodology) – specific grounding of the study's logic and criteria.
- Collection of data (method) – explicitness about data collection and management

- Representation of voice (researcher and participant as multicultural subjects) – researchers reflect on their relationship with participants and the phenomena under exploration.
- The art of meaning making (interpretation and presentation) – the process of presenting new insights through the data and chosen methodology.
- Implication for professional practice (recommendations)

The above elements need to be embedded throughout the research process explicitly and be an overarching principle of qualitative inquiry and an interactive process (Tobin et al., 2004).

In this study, a qualitative approach using grounded theory with its theoretical foundations drawn from Symbolic Interactionism was used as the foundation and methodology as described earlier on in this chapter. Data was collected using a digital voice recorder through focus group interviews and individual interviews; data was also collected from the medical notes of older South Asian men and women with Type 2 diabetes; all the data from interviews were transcribed by the researcher and both the audio and textual data are stored in retrievable forms electronically. Data was managed using NVIVO 2, a qualitative software.

Issues such as altered hierarchy, role conflict (researcher being a nurse professionally had the potential threat of ‘advising’ participants on what was right and wrong with their diabetes management), informed consent, confidentiality and the impact of the research event on the participant (a follow up focus group interview was done with the EHDWs to identify issues related to the interviews with non English speaking participants) in the researcher participant relationship were identified and addressed appropriately as discussed in this chapter. A conscious effort was made to maintain the “researcher” role and the “confidant” role (Wilde, 1992) which demands that personal and professional knowledge of the researcher be set aside while interacting with research participants. Individual interviews were conducted either in the participant’s home or community centre as desired by the participant to minimise the threat of altered hierarchy.

Data has been meaningfully interpreted and conclusions have been drawn culminating in the development of a conceptual model on risk perception among older South Asians with Type 2 Diabetes as described in a Chapter 9. Implications for practice, education and policy have also been identified from the data and presented in Chapter 10.

Credibility (Lincoln et al., 1985) – Includes activities that increase the probability that credible findings will be produced. It requires prolonged engagement with the subject matter, member checking – to see whether the participants recognise the findings of the study to be true to their experiences and the findings are validated by the participants.

To ensure credibility, the following was done.

Participant validation: All the interviews were transcribed in English and the transcripts were returned to participants wherever possible since there were literacy and language barriers among older South Asians. The transcripts of the non English speaking participants were returned to the interpreters for validation. All the transcripts were confirmed to be reflective and accurate and no amendments had to be made with the data following participant validation. The transcripts were returned to the health professionals and the focus group transcripts were returned to the Health Development Workers who were interviewed as part of the study for participant validation and were confirmed to be accurate.

Confirmability (Lincoln et al., 1985) – Confirmability is demonstrated through an Audit Trail that is able to illustrate clearly the evidence and thought processes that led to the conclusions or results. The audit trail helps with the assessment of confirmability and a carefully maintained log of the raw data, data reduction and analysis products, data re-construction and synthesis products, process notes, materials relating to intentions and dispositions and information on the development of the research instrument (interviews) will strengthen this process (Cutcliffe et al., 2004).

An audit trail was maintained throughout the research process to enhance confirmability, research diaries (hard copies / electronic) were maintained of all the research activities. All the raw data from the interviews (individual and focus groups) is held electronically. The reflections on the data were maintained as memos that were made possible with the software that was used for data management. Documentation of the discussions with the research supervisors held during the supervision meetings at regular intervals was also maintained electronically as part of the audit trail.

Triangulation (Denzin, 1988) - This involves the use of two or more theories, data sources, methods or investigators in a study to enhance the rigour of the research. It facilitates the collection of data from different perspectives or sources of the same phenomenon. Data or source triangulation that was used in this study maximised the range of data (Shih, 1998) that became available towards a more complete understanding of the phenomenon (risk perception among older South Asians with Type 2 diabetes) that was being investigated. Triangulation also helps to clarify meaning and verify the repeatability of an observation or interpretation (Lincoln et al., 1985).

Issues with regard to validity in order to strengthen the rigour were addressed in this study as below:

Triangulation was adopted at two levels to improve validity and reliability in this study.

- *Data / Source triangulation:* Data was collected from interviews and participant's medical notes.
- *Interdisciplinary triangulation:* (Denzin et al., 2003) Data from interviews with physicians, DNSs, dietitian and Ethnic Health Development Workers working among older South Asians with Type 2 diabetes.

Reflexivity (Ahern, 1999; Robson, 2002b) – Reflexivity is the realization that researchers are part of the social world that is being studied and the outcome of an honest introspection of the researcher’s values, belief systems and interest that may impact upon the research work that they are involved in. Reflexivity was used to identify potential researcher bias as described below.

- *Identified personal issues* – Culturally, it is unacceptable for the researcher as a woman to discuss issues related to sexuality even with her patients. Women in the South Asian culture are expected to be inhibited about expressing their own sexual needs even to their spouse. Despite her role as a practitioner (nurse) in India, issues concerning sexuality are not usually discussed with male patients in particular. Coming from a South Asian background, the researcher was aware that it would not be acceptable for the researcher being a woman to discuss about erectile dysfunction as a long term risk related to diabetes nor would the male participants be comfortable discussing about it. So, this area was not probed unless it was spontaneously brought up by the research participant.

- *Clarified personal value systems* – As a nurse by background and South Asian in origin with strong religious values and beliefs there were areas in which the researcher was subjective. These included experience with patients’ non compliance, the lack of importance South Asians in general attributed towards health and the role of external locus of control. A conscious effort was made to maintain the researcher role rather than the role of a nurse through out the study. The researcher refrained from sharing any of her beliefs or values with the research participants.

- *Identified potential areas of role conflict* - These include practitioner – researcher conflict (the tendency to ‘advise’ people

regarding effective management of diabetes and the prevention of long term risks) and the need to avoid giving advice or suggestions to participants about what they should be doing about their diabetes and to listen to what they had to say about their perceptions.

- *Identify gatekeepers' interests* - The study was undertaken purely to fulfill the requirements towards a doctoral programme of the researcher. There was no funding involved nor were there any other vested interests. The research proposal was subjected to ethical scrutiny and approval was obtained from the Northumbria University – School of Health, Community and Education Studies (HCES) research ethics sub committee, Newcastle and North Tyneside Local Research Ethics Committee (LREC) and Newcastle Primary Care Trust (PCT). There were no competing interests to be declared.

- *Identify feelings that cause the researcher to avoid or seek out situations* – Given the language barriers for the researcher and fluency in English, care was taken not to seek out only the English speaking South Asians. Representation from non English speaking South Asians (Nine out of the twenty interviews – 45 %) was also ensured despite the difficulties with issues related to interpretation. There were issues with recruitment of participants representing Bangladesh. Every possible attempt was made to have representations the Bangladeshi community (five out of twenty) in the study.

Peer debriefing and support: Presentation of the project with peer groups or discussion with experts in the field as a validation process was done throughout the research process. The project was presented to the Northumbria University Ethics review panel, the Local Research Ethics Committee (LREC), the diabetes

team at South Tyneside PCT, the team at the Regional Centre for Diabetes in Newcastle upon Tyne and to the International Risk and Ageing network between December 2003 and September 2004. Subsequently as part of dissemination, the project was presented at various stages in two International conferences in Rio de Janeiro, Brazil, (July, 2005) and in Bangor, Wales in September, 2006. The feedback obtained from these presentations was used to build up the risk literature and in the process of data analysis. It also affirmed that the research was worthwhile and that practitioners were looking for information on risk perception related to diabetes among South Asians.

The two other methodological issues that needed to be addressed were language (nine out of the twenty older South Asians interviewed were non English speaking) and the need to use interpreters. All nine of them consented to be interviewed using an interpreter.

Language

The level of ability to speak, read and write English varies considerably between ethnic groups. People from Pakistani and Bangladeshi backgrounds experience greatest difficulty (Chamba et al., 2000; Modood et al., 1997) . South Asian women are less likely than South Asian men to be able to communicate in English and this is more pronounced among elderly patients (Gerrish, 2001).

Interpretation

South Asians are known to prefer to have family members interpreting for them when needed. They are often wary of someone from outside their immediate community being privy to personal details. There have been reports where the South Asians feel that interpreters are part of their community and so what is said will get round the community. The interpreters are trained about confidentiality but patients may not feel able to trust them (Wray, 2003). There are also concerns

among the South Asians that professional interpreting was not confidential (Chamba et al., 2000).

Given the complexities around the issue with using interpreters, a lot of thought and consideration had to be given in planning the interviews. It was addressed as follows:

- A choice was given in the consent form regarding their preference to use a family member or an interpreter when there was a need for interpretation.
- The Ethnic Health Development Workers (EHDWs) were contacted through the Health Development Service and the Primary Care Trust and asked if they would like to act as interpreters for those participants who had consented to use an interpreter. This approach had many advantages and a disadvantage as outlined below.

Advantages

There were several advantages of using the EHDWs for the process of interpretation since they already had a rapport in place with the participants because of their role as service providers to them and hence weren't viewed as professional interpreters. The participants seemed to also be more open since the researcher was accompanied by the Ethnic Health Development Workers for the interviews. The EHDWs had previous experience of interpreting for health related research among ethnic minorities and also being employed in the National Health Service (NHS) were very familiar with the need for confidentiality. The cultural preference and social acceptance of using a gender matched interpreter as the participant was also possible with this approach. The EHDWs also shared a South Asian background. Out of the six EHDWs who assisted with the interpretation, three were women (one from India who could also speak Punjabi and Urdu and two from Bangladesh who could speak Urdu and Sylheti) and three were men (one from Pakistan who could speak Punjabi and Urdu and two from Bangladesh who could speak Urdu and Sylheti).

Disadvantage

Since the Health Development Workers were also involved in recruiting the participants for the study, one could assume that there would have been possibilities for selection bias. To eliminate this, the consent forms were reinterpreted in the presence of the researcher prior to the interview and the participant was requested to sign the consent form only if they were still willing to be part of the study. They were given the choice to withdraw even at that stage.

The interpretation process

Measurement tools for immigrants who are not native English speakers are usually based on their ease with using English for communication. The level of acculturation tends to be associated with the fluency and confidence with which an immigrant can think or speak in English. Consequently, the least acculturated often face many barriers with accessing resources of any nature and health care resources in particular. Therefore, any health care research among minority ethnic groups or immigrants that fails to include representations from non English speaking groups results in an inaccurate reflection of immigrant health care needs. It is also recommended that health care can be made more accessible to these immigrants through cross cultural communication in both clinical and research settings (Esposito, 2001). The fact that people using different languages may construct risk differently poses methodological and epistemological challenges (Temple et al., 2004).

Translation could be defined as the transfer of meaning from a Source Language (SL, such as Punjabi) to a Target Language (TL, such as English). When interviews are conducted in a language other than that of the researcher, there is a loss of spontaneity in guiding the interview with the language barrier. The opportunity for the researcher to analyse the data as it is being collected is also lost unless translation occurs immediately (Yelland et al., 1995). The real-time or instantaneous interpretation is recommended in cross cultural focus groups to ensure that the outcomes are closer to the quality of same-language studies. This also facilitates concurrent data analysis, the

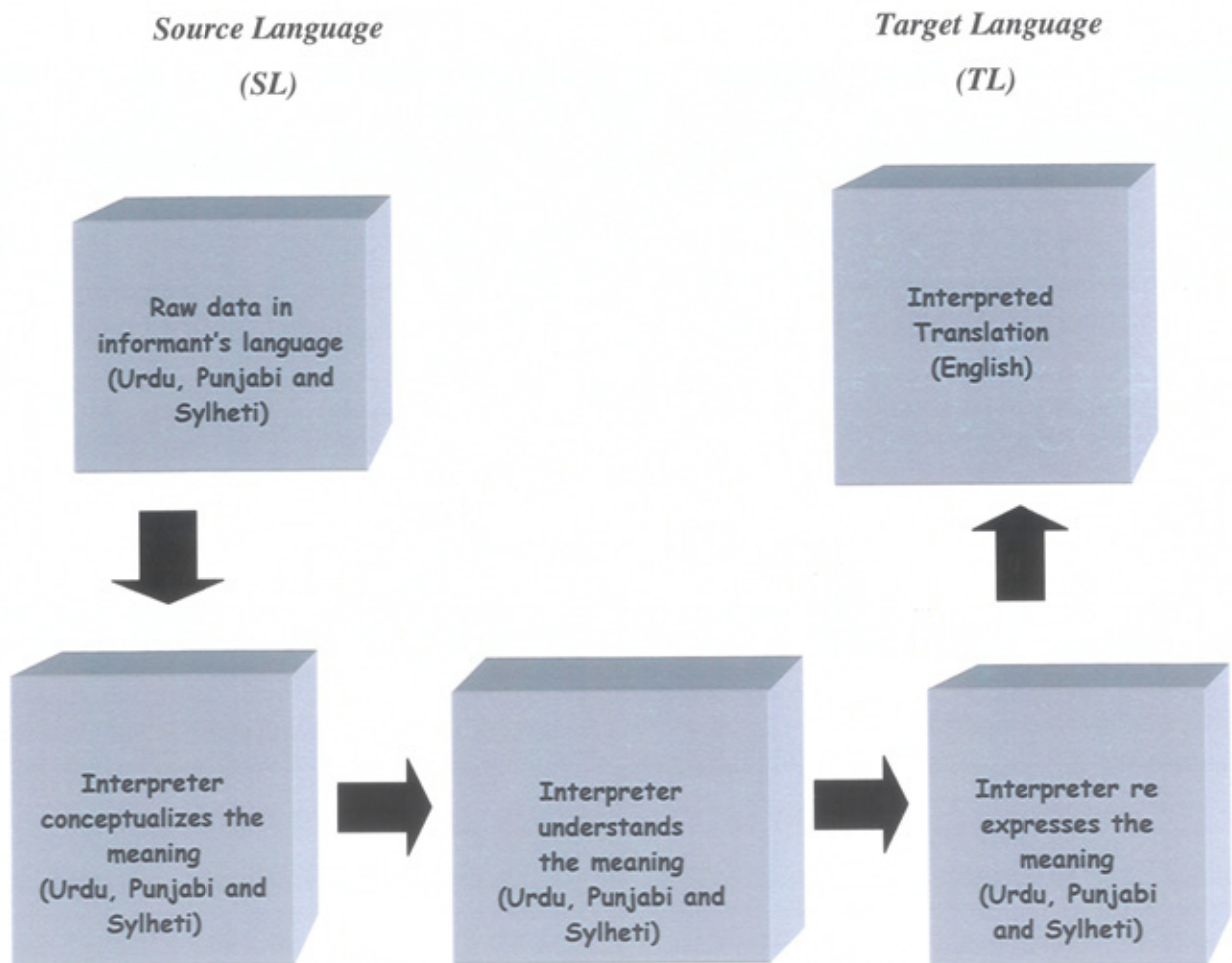
redirection of questions to the participants as required and the opportunity to validate findings through participant feedback (Esposito, 2001).

Recognising the methodological challenges within the language barriers in this study, the interpretation process was done as represented in Fig.5. The interpreter processed the vocabulary and grammatical structure of the words while considering the individual situation and the overall cultural context of the Source Language. The interpreter then conceptualized the meaning and, using vocabulary and grammatical structure appropriate for the Target Language, reconstructed the meaning of the statement in a new cultural context (Larson, 1998). This approach was used with all the nine interviews that were done using the Ethnic Health Development Workers for interpretation with the non English speaking participants in this study (seven with women and two with men).

This approach with real – time translation facilitated the possibility of redirecting any question to the participant as required and also an opportunity to validate the data as it was being translated. This was also confirmed by the EHDWs that it was useful to use the Cross Language process of interpretation rather than do the entire interview in the Source language (Punjabi / Urdu / Sylheti) and then translate it into the Target language (English) as described in the following quote during the follow up focus group interview that was done with them on issues related to interpretation and participants' experience with the interview.

“Sometimes it would be a bit more difficult for you because you don't understand the language, right? as to whether the person has understood the question you were asking. So it might be a case of the interpreter not asking the right question or they having a misunderstanding and you're not going to get the right response. So, I don't think that would be a very good idea to do that. At least when somebody else is simultaneously translating for you, then you have an idea that this person has actually understood the question and if not you can rephrase your question, yeah?” (Purva, Focus group)

There were no major issues with the process of interpretation that were reported.

The Process of Cross – Language Interpretation*Fig 7. - Cross – Language Interpretation (Larson, 1998)*

Each interview lasted for about an hour approximately and the first focus group interview lasted for about 90 minutes. All the interviews in both the phases were digitally recorded using the Olympus DW 90 digital voice recorder and were maintained electronically in retrievable forms. On one occasion there was a woman who declined to consent for the interview to be recorded since she wasn't comfortable with her language skills in English and notes were permitted to be taken. The interview was transcribed the same night in order to avoid missing out details. In another instance, while interviewing a male participant, there were technical

difficulties with the computer that was connected to the digital voice recorder in between the interview and so part of the interview could not be recorded. Notes were taken and added to the transcript. The health development worker who had accompanied the researcher for this interview validated the transcript to be very accurate and reflective of the entire interview process.

Focus group interview on issues related to interpretation

A short focus group interview was planned with the EHDWs at the end of Phase 2 of the data collection to discuss specific issues in relation to language barriers and to share their experiences with interpretation for this study. There were six EHDWs (three men and three women) who assisted with the interpretation during individual interviews but only two out of the six were available to participate in this focus group due to unavoidable circumstances (holiday, extended periods of sickness and observing fasting during Ramadan etc). The overall feedback to the process of data collection, participants' experience with the interviews and the experiences with interpreting for both of them was very positive. The very purpose of this qualitative research to give opportunities and hear the "insiders" voice (South Asians with Type 2 Diabetes) was achieved as expressed in the following quotes:

"They were happy when we did this interview. They said, they found that they have explored their problems to somebody. It was good actually, good experience..... They enjoyed this, all the ladies they enjoyed this interviews. Even they were so happy after the interview and they were thinking that they have achieved something." (Hita, Focus group)

"It's very useful. I found this research for our clients as well why we are working with them from a long time but still it's in their mind that there is something they are doing for us. Somebody else is doing.... They understand about these things. Somebody else is working for us as well. That's the thing. That's why the ladies were very happy. They are doing for us good for us, you know. They were very pleased about this." (Hita, Focus group)

Conclusion

The philosophical position chosen was the interpretive model of the Qualitative paradigm using Symbolic Interactionism. Grounded theory was the methodological stance as explained earlier on in the chapter. Data was collected primarily through focus group and individual interviews and the data was managed using NVIVO 2, a Qualitative software package. The principles of theoretical sampling, constant comparison, coding and categorizing, theoretical sensitivity, use of literature as recommended by the evolved form of Grounded theory were used and every attempt possible was made to ensure that the entire process was rigorous and transparent. The data analytical process using open, axial and selective coding based on grounded theory is described in the following chapter in detail.

CHAPTER: 4

DATA ANALYSIS

Introduction

Qualitative data analysis is an iterative process which actually begins with the conception of the project, progresses through developing the research design, data generation techniques and continues through data collection as discussed in the previous chapter. It is mandatory that the researcher ‘immerses oneself in the data’ (Swallow et al., 2003) for the data analysis to be complete and rigorous which will then result in the culmination of the theory regarding the social process being explored. Immersion does not just involve collection of data, the transcription and coding of the data but also reflection throughout these phases. Grounded theory analysis has ‘quite a lot in common with doing a jigsaw puzzle without the picture’ (Pearson, 1991). This chapter focuses on the influence of grounded theory and its relevant analytical approaches to data analysis. The various steps used in the analytical process are described in detail throughout the chapter.

Data Transcription

All the interviews (27 individual interviews and two focus group interviews) were transcribed by the researcher using the Olympus DSS Player 2002 transcription kit. The quality of the interviews was audible and clear because of the digital voice recorder and there were no difficulties encountered with the transcription process. The researcher transcribed all the interviews and this also facilitated the process of “immersion” (Swallow et al., 2003) with the data and assisted with the analytical process as the transcriptions progressed. A certain amount of theoretical sampling (that influenced both the people interviewed and the questions that were asked) was also made possible with the researcher transcribing the interviews and issues such as

resistance towards taking insulin and missing hospital appointments were explored further in detail in subsequent interviews as described in the previous chapter.

Data management using NVIVO 2

Software strengthens analytical rigour by improving transparency with the ability to be able to trace back to the original data in an easily retrievable form. It also facilitates efficient data management with large volumes of data. To facilitate the process of coding, categorizing and memoing, there are several commercially available software programmes. Data from this study was managed using NVIVO 2 that facilitates the iterative nature of qualitative research with options made available for memoing, creating data bites that can be hyperlinked to the database and creating document and node links during the coding process that could hyperlink with the original transcript. The reflective process that went on prior to and during the data collection could all be lost if they are not documented for subsequent analysis. NVIVO 2 enhanced the possibility of moving between coding, reflections and memo writing which preserves the iterative nature of data analysis. A licensed copy of NVIVO 2 was purchased and two associated training programmes were completed. All the transcripts were imported into the software for data management and data analysis. The figure below represents the special features of the software that help with data management.

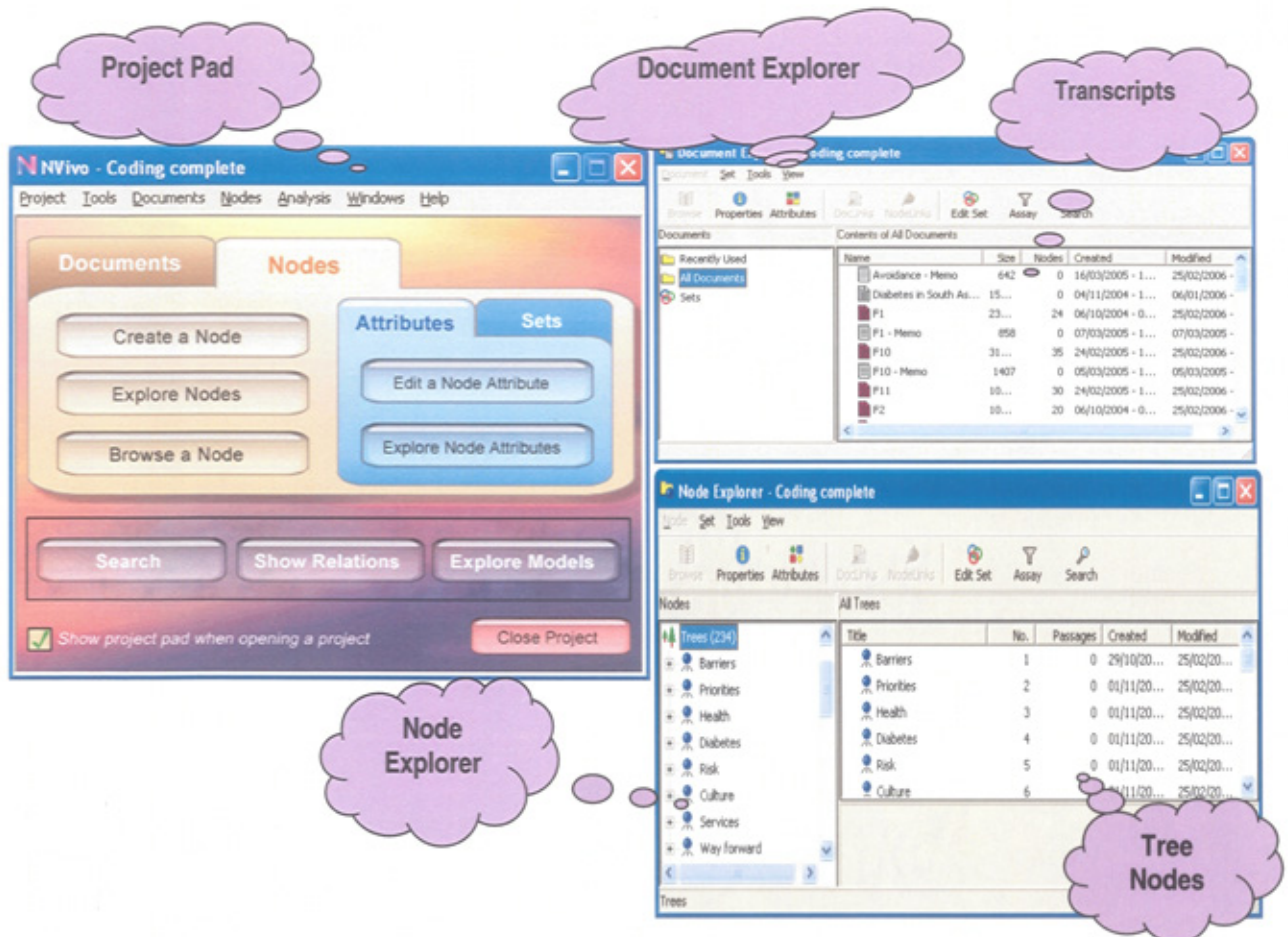


Fig 8. - Visual display of NVIVO 2

Using NVIVO 2 to manage the data from this study *improved analytical rigour* by providing a hierarchy of nodes which form thematic patterns. The hierarchy of nodes were 'a priori' nodes, which are themes that occur in the beginning and were discovered by the researcher in the first phase of data collection; 'emergent' nodes are those which emerge from research participants in the process of data collection and finally 'analytical' nodes which emerge from patterns emerging as a result of analysis (Gregorio, 2003). By assigning attributes or characteristics to documents or nodes, it was possible to search within these sets for patterns (QSR, 2002). The process of analyzing these nodes and memos was done in a hierarchical manner as well – open coding which is interpreting themes into a system of free nodes, axial coding which is linking together categories into a system of tree nodes and selective coding which is the selection and focus on one category that will explain and around which other categories are integrated (Robson, 2002a). It *improved transparency* through the use

of date stamping the whole process of analysis and by providing electronic audit trails, node and document links. Even memos could be date stamped and linked back to original transcripts and other related data. Thus, it became possible to trace back to every stage of the analytical process (Bringer et al., 2004). The demographic data of all the research participants were maintained in the form of a table by assigning various attributes to each participant. The modelling option from the software was not used. *Flexibility* was promoted by providing links to documents within and outside the project, text and other audio files (digitally recorded interview data), treating memos at the same level as documents (can be coded and linked) and links to other software such as the Endnote that was used for referencing (QSR, 2002).

Development of data analysis

Irrespective of the form of Grounded theory (Traditional / Evolved) that one chooses to use, there are common characteristics that are central to any Grounded theory approach such as treatment of literature, theoretical sampling, constant comparative method, coding and categorizing, memo writing, theoretical sensitivity, measure of rigor and identifying the core category (McCann et al., 2003b). To answer the research aims of this study (develop a conceptual model on risk perception in older South Asians with Type 2 Diabetes in the United Kingdom), the evolved form of grounded theory was adopted and data was analysed as follows.

Treatment of literature

The point at which literature needs to be reviewed or utilised in the research process within Grounded theory is heavily contested between the traditional and evolved forms of Grounded theory. As discussed earlier, Glaser's recommendation is to withhold reviewing literature in the substantive area under study (Glaser, 1992) to overcome any contamination or impediment with the analytical process (Mills et al., 2006). This approach also suggests that the data is a separate entity from both participants and researcher.

The evolved form of Grounded theory on the contrary, advocates proactive engagement with the literature from the beginning of the research process (Strauss et al., 1998). 'Interweaving the literature throughout the process of evolved grounded theory as another voice' (Mills et al., 2006) will enhance the researcher's theoretical reconstruction. Similar to the use of theoretical sensitivity, the use of literature would be able to provide new insight and different perspectives into the data analysis.

For the purpose of this study, literature was used from the initial stages of the study. The researcher was not very familiar with the concept of risk in the early stages of the study and the literature on health related risk was very helpful in identifying factors that impacted upon risk perception and designing the interviews in addition to the theoretical sampling that was used as described earlier. Data from the literature also ensured that critical aspects around risk (Element of choice, agency etc) were not missed out during the interviews. Similarly, being a member of the International Risk and Ageing network enabled cross cultural interaction and sharing of literature on issues around 'Risk'. Interactions within the network provided new insights and perspectives such as the possibility of a Risk continuum within which people operated when challenged with decision making around issues related to 'Risk'. The continuum of beliefs and behaviours ranged between Risk Philia and Risk Phobia and involved personal values, ability and the power to make choices, agency of the individual and other stakeholders in the process of decision making and negotiation (Clarke, 2006).

The use of literature throughout the research process certainly enhanced and stimulated the thought processes rather than stifle or inhibit the researcher. It widened the horizons and possibilities for the data to be examined more closely during the theoretical coding in particular. Of particular importance to this stage of data analysis were the theoretical frameworks of the Health Belief Model (HBM) (Rosenstock, 1985), cultural theory (Douglas et al., 1982) and the Theory of Planned Behaviour (Ajzen, 1991, 2002a; Ajzen et al., 2007).

Theoretical sensitivity refers to the researcher's knowledge, understanding and skill which foster the generation of categories and properties and increase their ability to relate them to hypotheses and to further integrate the hypotheses according to emergent theoretical codes (Glaser, 1992). Traditional grounded theory requires that researchers enter the field of inquiry with as few preconceived ideas and thoughts as possible on the social process that needs to be explored in order to enhance researcher sensitivity to the data.

However, the absence of theoretical sensitivity will result in a combination of empirical description with some preconceived conceptual description (Strauss et al., 1990). Professional experience, personal experience and in depth knowledge of the data in the area of study facilitate substantive sensitivity that is necessary to generate categories. This along with the conceptual ability will assist the researcher to generate theoretical codes. These theoretical codes would then enable the researcher to see the data and concepts in a new way to generate theory or conceptual hypotheses and their integration.

Theoretical sensitivity was adopted along with reflexivity for this study in the following ways. The researcher's professional experience as a nurse practitioner and personal experience of being a South Asian herself provided valuable insight into every phase of the project such as designing the interviews, appreciating the context of the participants and the generation of codes and categories (e.g. – Locus of control). The researcher also had the opportunity to join the International Risk and Ageing network in the course of the project and her interaction with other members of the network and participation in the related annual meetings and symposia widened her perspectives on the concept of risk especially during the theoretical coding process. Opportunities to publish scientific papers on 'Risk' (Appendix 12) through the network also improved theoretical sensitivity and grasp on issues around the concept of risk. It helped crystallise the researcher's conceptual ability on the theoretical codes that were beginning to emerge.

Constant Comparative Analysis

A researcher using grounded theory is expected to maintain theoretical sensitivity throughout the research process. This would enhance the possibility of the theory that is generated being grounded in the data rather than on assumptions or pre existing theories. The constant comparative analysis facilitates stimulation of the thought process about the data, concepts, categories or themes that emerge thereby enhancing theoretical sensitivity and the focus for theoretical sampling (Jeon, 2004).

The process of constant comparing and asking relevant questions are embedded in the entire research process which sharpens the researcher's thinking and facilitates understanding of what is in the data. The emphasis is to clarify concepts derived from the data along with producing precise descriptions (Jeon, 2004). There are four stages in the constant comparative method as follows (Glaser et al., 1967).

Comparing incidents applicable to each category

Integrating categories and their properties

Delimiting the theory and

Writing the theory

The use of comparative analysis is for generating 'theory as process; i.e. theory as an ever-developing entity, not as a perfect product' (Glaser et al., 1967). This gives the theory that is generated its credibility or trustworthiness that can be understood only within the context of the social world from which it was derived. The specific purpose of constant comparison in grounded theory is to facilitate the process of conceptualization and coding of categories during the collection and analysis of data in order to ensure that the theory that is generated is grounded in the data rather than anything else. It would therefore not be relevant if the data is interpreted outside the context (Jeon, 2004).

The unique features of NVIVO2 as described earlier on in the chapter, facilitated and enhanced the possibilities of moving between the data and categories and thus fostered constant comparative analysis of the data from the very early stages of data analysis.

Coding and Categorizing

Coding of data begins early in grounded theory and it enables data to be defined and categorized as it is collected. It is the initial phase of the analytic method, which is simply the process of categorizing and sorting data (Jeon, 2004). Coding helps to manage unstructured data and also guides the focus on further data collection; it facilitates conceptualization of the data, the building up of the theory from the data and also determines the quality of the theory that emerges. It is a very vital process that links raw data and the emerging theory in order to empower the theory with explanatory power. Glaser describes the process of data analysis in grounded theory in three phases. 'Input' is the first phase, the data moving as part of the researcher's thinking. It is difficult at this stage to see how the codes are connected to each other or the emerging theory. The second phase is called the 'drugless trip' where the data are in the researcher's mind. Different ideas emerge about the theory but without any clarity. Connections between the codes can be established through axial coding which is both an inductive and a deductive process. However, the process can still be abstract. The third phase is called 'saturation' where the researcher writes down the results from the analysis of the data and draws conclusion leading on to theory development (Glaser, 1978).

Analysis of data in grounded theory involves three sets of coding (Robson, 2002b) - open, axial and selective coding.

Open coding: Involves the initial fragmenting of data to explore all the possible aspects or information about the phenomenon being studied. This results in the development of descriptive codes or categories from the initial data gathered.

In this study, all the 29 transcripts were subjected to open coding by assigning meaningful topic names to each line of the transcript. An example of open coding is shown in the figure below.

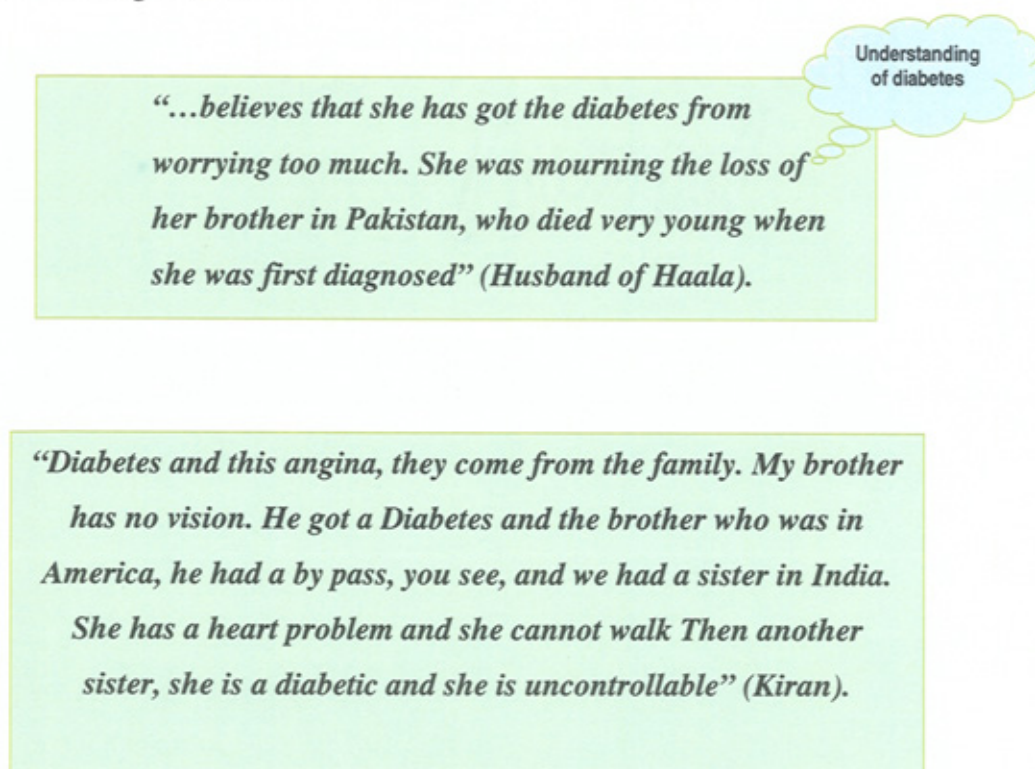


Fig. 9 – The Process of Open Coding

Axial coding: This involves the development of a coding paradigm which identifies a central phenomenon, explores causal conditions, specifies actions that result from the phenomenon, identifies the context that influences these actions and the outcomes of the phenomenon. In this level of coding, the descriptive codes are grouped at a more abstract level and linked by relationships that emerge from within the codes. The phases of open and the axial coding together can also be known as substantive coding which enables conceptualization of ‘the empirical substance of the area of research’ (Jeon, 2004).

Axial coding consists of intense analysis around one category at a time that facilitates understanding about relationships between that category and other categories and subcategories (Strauss, 1987). This increasingly dense conceptualisation enables links

to be made between categories. In axial coding, which is also known as theoretical coding (Strauss et al., 1990), comparisons are made between codes to enable links to be made between them, making the emerging analysis denser. Analysis at this stage requires inductive and deductive thinking and making comparisons within data (McCann et al., 2003a). In the present study, one example of the outcome of axial coding was the linking of a number of codes about understanding of diabetes with codes about impact of diabetes on risk perception. These codes were linked as a result of axial coding and the category of personal factors affecting risk perception emerged.

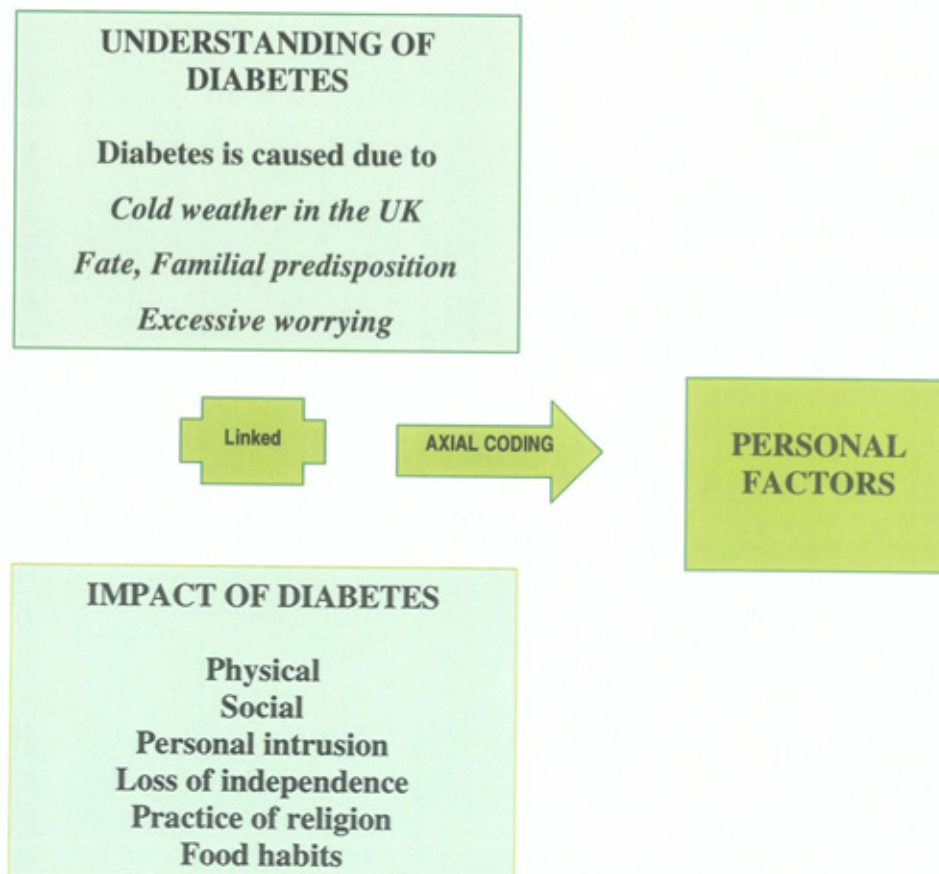


Fig. 10 - The Process of Axial Coding

As the emerging pattern from open coding became clearer, the free nodes were then classified and analysed using axial coding into tree nodes. The axial coding resulted in categorisation of the data as shown in the figure below.

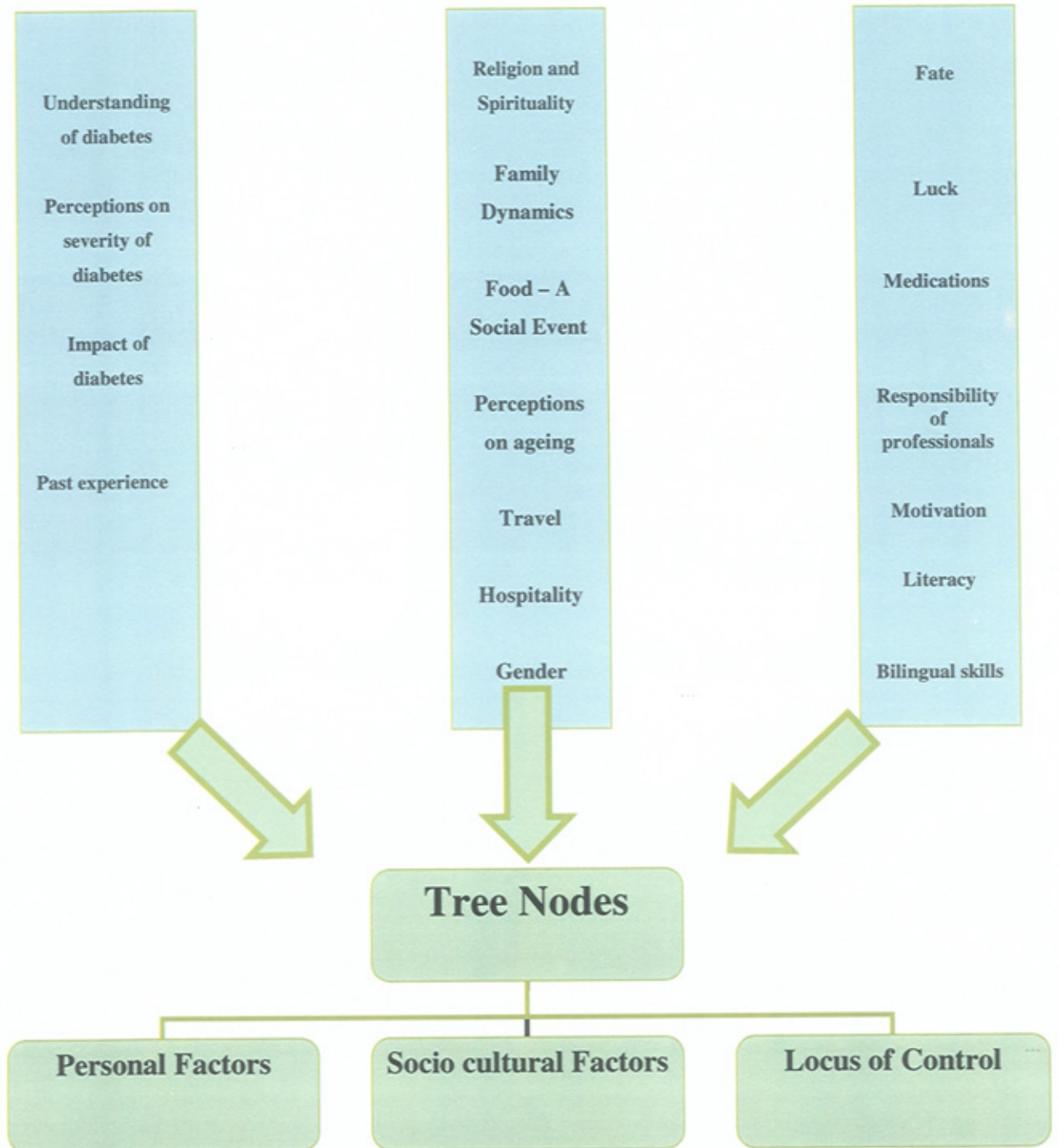


Fig. 11 – Categorisation of data

Selective coding: This involves the integration of categories from the axial coding forming conceptual links that facilitates development of the theory.

This level of coding aims to identify a core category that establishes links between itself and other categories (Charmaz, 1990). The important features at this stage of analysis are theoretical coding and memo writing. This enables the data to be perceived theoretically rather than descriptively. The core category that results should be dense but comprehensive and conceptualise the links between all three levels (open, axial and selective) of coding in addition to being able to explain variations in the categories (McCann et al., 2003a). Interpretation of the data was done using selective coding forming conceptual links by integrating the categories that were arrived at following the axial coding. The categories were then assigned to theoretical nodes that described risk awareness, risk engagement, risk response, and ranking of risks among older South Asians in relation to their diabetes. The figure in the following page represents the analytical trail.

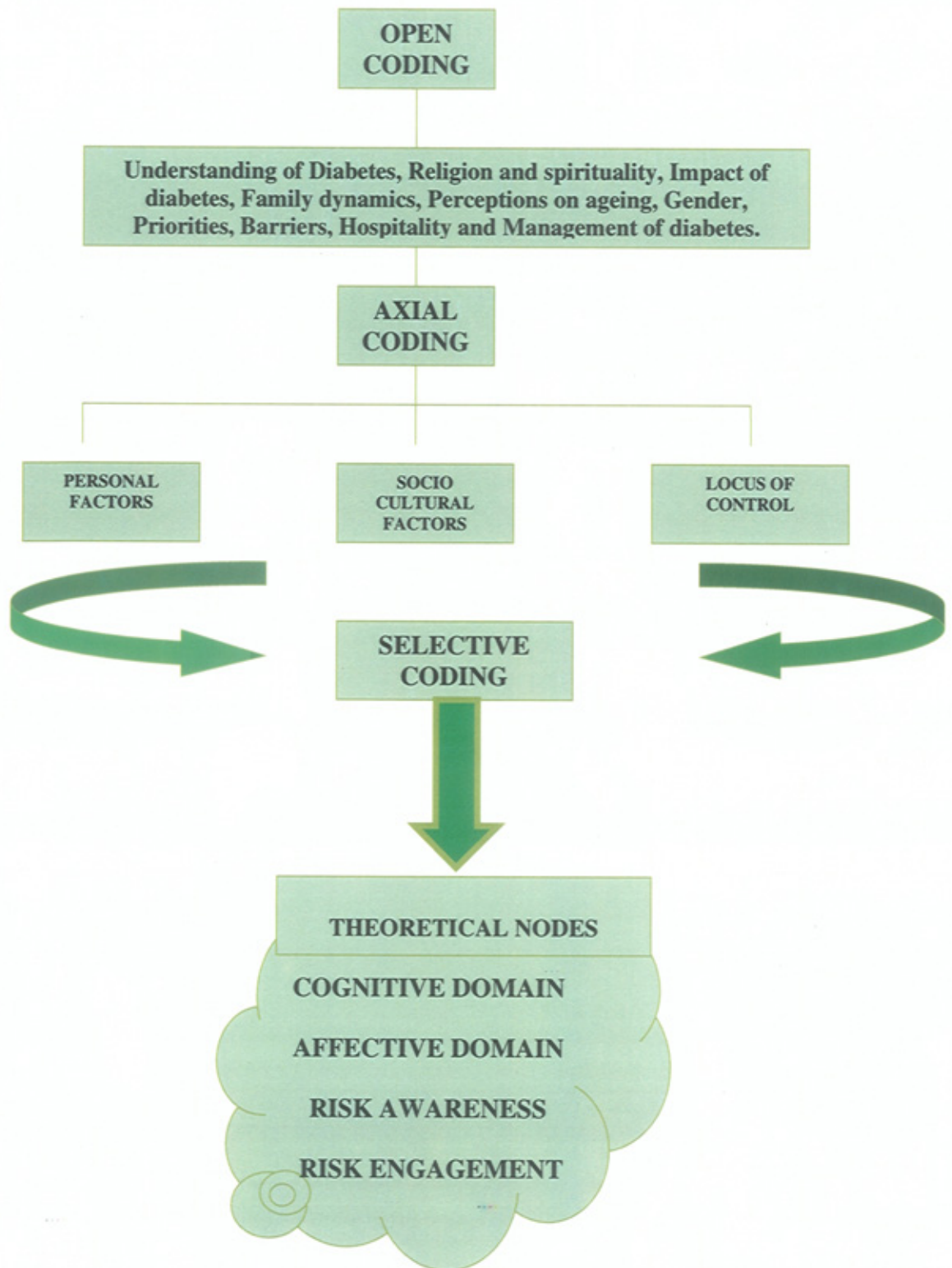


Fig.12 – The Process of Selective Coding

Memo writing

The reflective process that accompanies data analysis is very valuable and needs to also be treated as data and subject to analysis. This therefore requires documentation which is retrievable as required. The iterative nature of analysis can be lost if these phases are treated sequentially without keeping a record of the reflections that occur simultaneously (Gregorio, 2003).

Thus, memo writing is the other essential core physical task along with coding in the analysis of qualitative data. Memoing enables the researcher to synthesize data, build arguments and attempts to link data together. Coding and memo writing are done concurrently and they inform each other as part of the analytical process. As the coding process gets more refined, the researcher makes memos on specific themes based on the reflections over the data and these are called elemental or small piece memos (Gregorio, 2003). With several such memos which also become the focus of analysis they build up as sorting memos. Sorting memos become an analysis on the preliminary analysis of data and are much more abstract. They also facilitate the thought process towards theory development. The next level of memos are called integrating memos which highlight the explanations and relationships between different memos are helpful towards developing conceptual framework and theory building.

Following were some of the memos that were created as the data was transcribed and analysed. These memos could also be date and time stamped which enhances confirmability with the possibility of being able to trace back to the development of thought processes through the analytical phase.

Elemental memos

There are some interesting issues as follows that have emerged from the Focus group interviews. These have been obtained by open coding with the open codes indicated in italics.

Spirituality and diabetes; Beliefs in predestination and fate; People discontinue treatment for their diabetes when they travel back to their country of origin (**Travel back home**) since they believe that the diabetes stays with them only while they are in the UK (**Management of diabetes**); There is a general awareness on related risks (**Diabetes and risks**) but people don't take it on board due to immediate priorities, other commitments (**Priorities**) and simply because they can't see the complications (**Diabetes, the invisible**) . Their social / religious expectations seem to have a higher priority.

Sorting memos

People's religious faith seems to be the driving force for health behaviours especially among the Muslims. In terms of taking risks, they would much rather take a physical / health related risk but not a spiritual risk because of their beliefs in the life after death and having to face judgement. (? Prefer / choose to face human judgement than Divine judgement). The following quote clearly illustrates people **weighing up or ranking risks** prior to engaging with the risks.

“People do give up their normal lifestyle and concentrate more on their religion and reading the Quran during Ramadan. They forget about everything else including hospital appointments. Whoever you are, Muslim or Christian, if you have a very strong faith, it somehow carries you through. That seems to be the most important thing in their life. This friend of mine had an appointment for a knee replacement for a long standing knee problem but decided to give that up and thought it was more important to go to Mecca with us instead”. (Dhiren).

Integrated memo (Analytical Memo)

Despite **risk awareness**, people engage with risks differently. **Risk responses** varied from helplessness to depathologising their diabetes in responding to the risks around diabetes. People seem to **engage with risks** either **proactively or reactively**. Individuals with a family member as a health professional, internal motivation and

bilingual skills seem more inclined towards engaging with risks proactively. There is a strong element of external locus of control especially in individuals with communication barriers that influences them to engage with risks reactively.

Evolution of the Conceptual Model

The data analysis led to the identification of the basic social process of risk perception that encompasses both risk awareness and risk engagement. The processes of coding, categorising, constant comparison and using theoretical sensitivity facilitated and refined potential connections between the concepts identified and resulted in the following conceptual model.

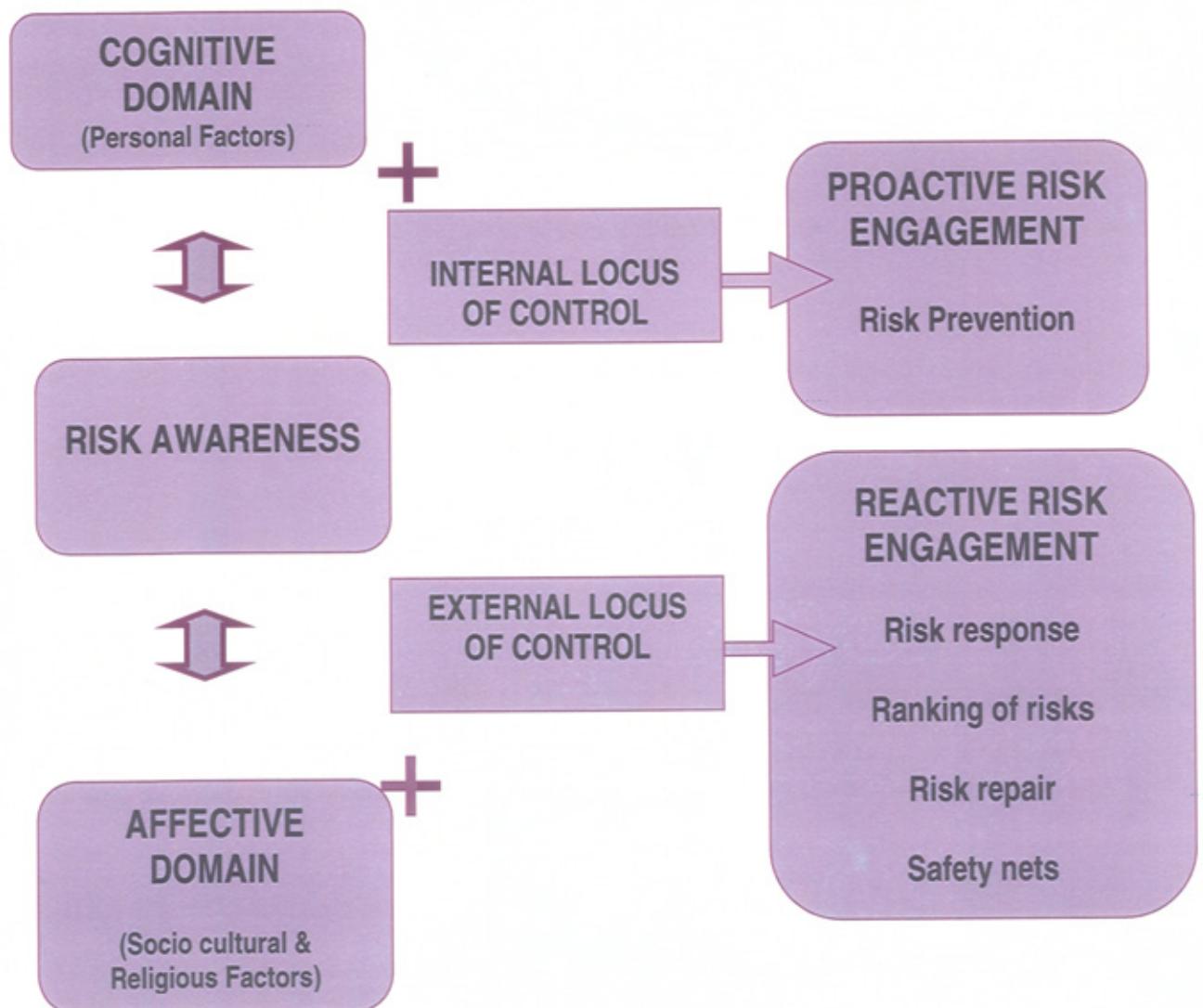


Fig. 13 – Type 2 Diabetes and Risk Perception

Personal factors such as South Asians' understanding of diabetes, their perceived severity of diabetes, personal experiences with diabetes related risks, the lack of immediacy and visibility of the risks proposed represent the cognitive domain. The socio cultural and religious factors represent the affective domain. Both internal and external loci of control influencing risk perception were evidenced from the data. Personal factors that involved the cognitive domain and socio cultural / religious factors that involved the affective domain along with locus of control resulted in risk awareness followed by risk engagement that was either proactive or reactive. The two predominant domains involved in risk perception in older South Asians with diabetes were the cognitive and affective domains and both these domains interact with each other through the dynamics of locus of control (internal / external). Each component of the conceptual model that emerged from the findings of this study is further discussed in detail in Chapter 9 and its implications for practice, education and policy towards diabetes management are discussed in Chapter 10.

The five subsequent chapters describe in detail the findings from this study as follows:

1. Cognitive domain
2. Affective domain
3. Practitioner – South Asian perspectives on risk
4. The Way Forward
5. Risk awareness and engagement

Conclusion

This chapter initially discusses approaches to analysis, in particular highlighting the approaches used to categorising data and the levels of analysis using grounded theory. The data analysis resulted in the above conceptual model on risk perception in older South Asians with Type 2 Diabetes which was the primary aim of this study. The various stages of the development of the conceptual model have been outlined in detail in relation to the analysis of data.

CHAPTER: 5

RESULTS

THE COGNITIVE DOMAIN

(Personal factors influencing Risk perception)

This chapter focuses on the findings as they emerged from the qualitative data that was collected for the study. As discussed in the previous chapter, the personal factors represent the cognitive domain. Understanding of diabetes, impact of diabetes, perceptions on the severity of their diabetes, their personal experience with diabetes related risks and issues around management of diabetes were identified as the predominant personal factors influencing risk perception among this group. Risk perception being very subjective, ideology loaded (Lupton, 1993) and a socially constructed concept, it is often quite difficult to draw definite conclusions about how one perceives risks in a given context.

Understanding of diabetes

Those interviewed, attributed their diabetes to being the consequence of a range of issues such as worrying too much, having eaten too many sweets in the past, cold weather in the UK, fate and familial predisposition.

There were women in particular who attributed their diabetes to being stress related since they were either going through bereavement or a difficult situation within their family at the time of their diagnosis as described in the two quotes below.

Maasma from Pakistan stated that *“There was something in our family that I worried so much that time (time of diagnosis) you know. Could be with that. That’s what people have been telling me you know. There was a big problem in our house you know. Not in my house but my relatives and that you know. That might be the reason, I’m not sure, may be.”*

“...believes that she has got the diabetes from worrying too much. She was mourning the loss of her brother in Pakistan, who died very young when she was first diagnosed.” (Husband of Haala)

The interpreter of Baqeer from Bangladesh stated that diabetes results from having eaten too many sweets in the past and that some such people could still get away from having diabetes. Despite taking precautions (cutting down sugar in his coffee and tea) after his wife was diagnosed recently, it didn't spare him. *“He doesn't know much but all he knows that it's (Diabetes) from having too much sweets and it's just a matter of whoever gets it gets it. It's like somebody has two, three spoonfuls of sugar in their tea and they still don't get it. He used to take only half a spoon of sugar because she (wife) was diagnosed to have diabetes and still got it.”*

Galina from India said that she believed that her diabetes was due to eating too many sweets in the past – *“I think so because, my inside sugar too much hey na, that's why. You know, India, we eat all the time sweet thing a lot you know, India, you know, because my dad got everything you know, Indian sweet day and night” ...*

The rich food available in the UK, cold weather and the lack of sunshine were attributed as being responsible for their diabetes and general lack of health.

“I think, it is the richness of food in this country and all the chemicals that they use for everything. It is also cold and back home there is sunshine. Sun is health.” – (Maahir)

This seemed to resound with the belief that south Asians held in relation to the sun's heat burning off the calories from the food they ate while they worked hard in the fields as Daanaa from Pakistan shared – *“...When I was there, people were drinking ghee because you know, when harvest comes, you work with the oxen, I worked at that sort of thing, ploughing, because when you are eating they all go out in your sweat, that's true. What a lot of people used to drink pure ghee in them days....”*

A woman from Bangladesh attributed her diabetes to a spiritual fate as in the following quote – *“Actually we don’t believe in these things. You know, how in this country they do believe like I should have been in good diet from childhood then I might not be getting it. We don’t believe in that. Our fate is totally different. It’s like you think, Allah decided to give you the illness, He will. No matter how well you are or how healthy you are.”* (Interpreter of Chandana)

Kiran from India stated that diabetes comes from the family as described in his quote – *“Diabetes and this angina, they come from the family. My brother has no vision. He got a Diabetes and the brother who was in America, he had a by pass, you see, and we had a sister in India. She has a heart problem and she cannot walk. Then another sister, she is a diabetic and she is uncontrollable.”*

However, there were instances of men identifying lifestyle factors and the lack of insulin as being responsible for their diabetes. Interestingly, one of these men (Anil) had a job within the health services and the other (Baahir) had a son who was a medical practitioner.

“Being a bit more knowledgeable, you know that you can’t really, there’s no really cause to being a diabetic. Parents etc.. their lifestyle, lifestyle changes do have a part to play.....” (Anil)

“I don’t know whether it is genetic or not. What they say is this insulin, my body has stopped or not producing more insulin. It may be that.” (Baahir)

There was another interesting perception that diabetes is probably caused by advances with civilisation, change in dietary habits and the use of chemicals in agriculture. It was also perceived that replacement of manual labour with machinery resulted in a sedentary lifestyle and restricted the opportunities to burn the calories as quoted below by Daanaa. Daanaa’s daughter was also training to be a dentist.

“It’s just the kind of food anywhere. At that time, when we were young, we are from the villages, my father when we did farming we just left the land to lie in fallow for three to six months. For six months it grew crops. Now it is not left for five minutes and these chemicals... The production of chicken, there was no such chicken before, they are chemicals..... We belonged to India at one time, all the old people used to say that they used to eat large amounts of everything but now you can’t eat much. They were so healthy. Still people are used to working hard at that time but everything is machinery now. You were doing everything with your hands before.”

There was a limited understanding of the diabetes as expressed by Sa’ood from Pakistan in the following quote. The understanding of diabetes in this case seemed to be that he was licensed to have sweets as long as long as he took the medicines alongside and that would balance his glucose levels.

“Even now, I feel sometimes you know, I’m not worried. The perception you know, I think is it’s very well controlled actually and I’m on tablets and I have a sweet tooth you know, I eat everything. There’s no restriction. I eat sweets etc. Those tablets keep it very well controlled between 4 and 6 (glucometer readings of his blood glucose levels) which is not bad. So, sometimes I feel personally that if I stop taking tablets and stop eating sweets it will be alright..... It’s cancelling that extra sugar that I consume.”

Understanding of diabetes also involved that the diabetes was part of them only while living in the UK. There were misconceptions that the diabetes was non existent while they travelled back to their country of origin. This had implications with the way risks were perceived. Obviously, the South Asians involved in the following quotes didn’t understand that diabetes was something physiological and not transient or the discontinuation of treatment would predispose them to significant long term risks. Given the premise, that South Asians believed that cold weather and lack of sunshine in the UK is what had contributed to their diabetes, they were then justified to believe

that the diabetes was non-existent when they went back home where there was plenty of sunshine.

“The typical problem might be that the patient has gone back to Pakistan or wherever and stopped their medication either on the advice of somebody back there or more likely on some vague pervading health beliefs like “You don’t need it when you are eating your normal local diet”. And that’s the commonest problem.” (Malcolm, Practitioner)

“I saw her before she went (to Bangladesh) because they kind of trot back and it took a bit to keep track of them and she came back and said ... She was a Diabetic before she left. She went to Bangladesh and they said she wasn’t Diabetic. So she was coming back here to see if she was really diabetic and her HbA1C was 8.3...” (Lyn, Practitioner)

“My, one of my clients came back from Bangladesh. When she went, she was like Diabetic and when she went she wasn’t taking her tablets on regular basis. So she has come in very serious illnesses. So she has to come back..... But her husband was saying “Once you are there, you don’t have to take medications...” (Teja, Focus group)

Perceptions on the severity of diabetes

Perceptions on how severe or poorly controlled one’s diabetes was, ranged from being on insulin or not, the number of tablets they take, frequency of hospital visits made and the type of services accessed (GP / Regional Diabetes centre) contrary to the practitioners who looked at an individual’s HbA1C (Glycosylated Haemoglobin) levels and other clinical parameters. This seemed to affect their perceptions on risks related to diabetes. However, people seemed more familiar with measuring their control of diabetes with the home glucose monitoring system.

“I’m alright, not too bad. Therefore not to really worry, you see. They call me only once a year. Some people go there (the Diabetes centre) every month, someone every three months. It’s all different ways.” (Abhaya)

“One doctor is quite willing to refer you to the Diabetes Centre and the other one says, “No. come to my surgery.” And for somebody who has been given that message, “O! He is going to the Diabetes Centre. So, he must be more serious than I am because I am just going to see my doctor.” - (Dhiren, Focus group)

“Because I know a few friends. They’re all on two tablets a day. Some I know, another few they are taking one injection.” – (Saadya)

Type 2 diabetes is quite commonly seen within South Asian families and this seemed to minimise or negate the seriousness of it as described by one of the participants in the focus group – *“Because it’s now in almost every household. It’s only Diabetes and nothing serious. It’s not cancer, you know, like we are not goin’ to die from it. Even though from Diabetes, you can eventually, I don’t think people see it that seriously.” (Juhi, Focus group)*

Diabetes was also depathologised as an illness and considered to be “normal” by some individuals depending on whether they were on medication or not – *“Nothing at all. You see, in my case, it is normal and on the margin, borders. It’s not much. Otherwise, if you have to take two or three injections daily, that becomes eh, you feel difficult having to do it.” (Baahir)*

Impact of diabetes

Physical impact (Fatigue, Mobility & Vision)

Diabetes seemed to have several significant impacts on South Asians and affect almost every sphere of their lives. The physical, psychological, spiritual, social and

sexual domains of their lives had been involved for both men and women. It was viewed as an intrusion in their personal lives taking control of what they ate leaving them very frustrated. They were aware of the chronicity of the disease and the lack of a permanent cure as evidenced in the words of Maasma, from Pakistan.

“This Diabetes, can it not be like stopped or finished? That’s what I’m thinking. Once and for all, it goes with your life I think and sometimes your life is finished with this Diabetes. I tell people, “It can’t be.” Once it started, it doesn’t finish.”

The physical impact was mostly described by women in terms of fatigue, tiredness, inability to do house work. This was reported to have affected their ability to go out as often as they would have liked to.

“She used to have a more active life. She used to go shopping, out a lot but she can’t do that now. She is generally not able to go out that often. As soon as she does a little bit of housework, she feels tired.” (Interpreter of Ila)

Peripheral neuropathy was another common physical impact related to their diabetes which was again mostly described by women. It was associated with excessive pain and discomfort that interfered with their ability to go outdoors (shopping) which they enjoyed. With walking being recommended as a helpful exercise in controlling the blood glucose levels, there was a strong sense of frustration with this impairment as described in the following quote. However, this wasn’t associated to be due to her sub optimal control of diabetes.

“I’ve been everyday, start my feet and all, you know my feet, come and gone pain, my feet, only one feet, now two feet now. Just this one make me killing my , you know, can’t walk, you know, my daughter all the time angry and say, “Mum, you little bit have walk, little bit go outside.” Me say, “How you want me go outside because pain hey na? And when I little bit go to a couple of shop, you know, I’m aching leg pain, I say, “I better go home.” (Galina)

Personal intrusion & loss of independence

Having diabetes was viewed as an intrusion in their personal lives since it involved restrictions around one's life style and the freedom that was curtailed even with basic issues such as food. Foods being such a central part of the South Asian culture, the limitations imposed by diabetes were perceived to be difficult. Interestingly, the kind of food one eats was also associated with their prosperity and the ability to afford food. The food restrictions that were advised by the professionals as necessary for diabetes management created a sense of regret and personal intrusion in one's life. This is very apparent in the words of Maahir, *"I'm talking about many, many years ago you know, many, many, many years before we came up here, we were craving because we couldn't get meat and things like that because poverty those days, you know and now here, we have the resource, we have the money, we got everything but the doctor says, "No. You cannot eat that now."*

The same gentleman (Maahir) was also affected by stroke due to his diabetes and was deeply distressed about the disability that came with it. He blamed his diabetes for having thwarted all his retirement plans stating, *"I had a lot of plans for myself you know, for near my retirement. Lot of plans but everything just went through the window now, you know. Lot of hobbies, I wanted to do, you know, when you work for a number of or over the years, you say, "When I have free time, I'm going to do this, I'm going to do that, I want to do travelling, you know. Everything went down there" (Points to the window).*

He also viewed diabetes as being responsible for the loss of his independence especially with his mobility and inability to drive following the stroke. It had caused him a lot of unhappiness since he was compelled to watch television which he didn't enjoy previously. The ability to be mobile and drive obviously meant a lot to him and signified his independence. He expresses his frustration very clearly in the following quote.

*“I lost my independence. Yes, I had lot of plans. Nothing ***** Watching this damn thing (Points to the television) everyday. I was never pleased, I wasn't a television guy. I'm like a couch potato. I never watched these things. I was out all the time previously. Oh, it's terrible. It's terrible you know because I had a stroke also on my left side now.”*

Impact on diet

“Watch what you eat, all the time”

During the interviews, most peoples' understanding of the dietary restrictions required for diabetes management was to cut down the intake of sugar in their tea and coffee rather than the more widely advocated monitoring of carbohydrates.

“As I said in the beginning, I stopped all my sugar. No sweets, no butter and things like that but now I do nothing. I just eat as everybody else eats. I had given up sugar altogether in the hospital in Delhi when they found out that I had Diabetes. Since then I haven't had any sugar in my milk or tea.” (Padma)

Their knowledge of having to cut down fat and fried food was predominant since most people mentioned that they had either changed their cooking oil to sunflower / olive oil as recommended and avoided fried food / snacks except occasionally.

“Well, I don't have much like grease things you know, like oil things. I have like dry things. I try my best you know but sometimes, when they are taking samosa and them, I'll just try one or two you know. Sometimes you feel like that every now and then. I'm used to the semi skimmed milk, the margarine is low fat. I don't use much margarine.” (Maasma)

People often confessed that they were aware that sweets were forbidden but they still continued to have them in small amounts.

*“I still eat some sweets you know to tell you the truth but very small amount.”
(Hadarah)*

When Sa’ood was asked if the dietary restrictions affected him, he replied *“It should have actually; if I put restriction on me if I don’t want to eat sweets and this and that, might be you know. But wherever I go, whatever is on the table you know, I enjoy fully.”*

Padma, whose diabetic control is excellent said, *“....but now I have found that if I eat you know, a little bit of Indian sweets or even the chocolates or anything, it doesn’t hurt me. So, I’m not that careful these days because I know that it doesn’t affect but I don’t eat too much of the sugary things. A little piece is alright.”*

There was a belief that eating sweets made someone stronger and the restriction with sweets caused the individual to become weak as in the following quote – *“Because of the diabetes, I can’t eat anything that is sweet. Otherwise I would have my strength.” (Maahir)*

Diabetes had a significant impact on peoples’ diet and food habits. There was a sense of loss with the freedom to be able to eat what they wanted and had to be constantly watching what one ate – *“You have to watch what you eat all the time. Previously, I could eat what I wanted.” (Haala)*

Participants expressed that they missed certain food that they were normally fond of and were quite negative about the restrictions as described in the following quotes.

“I was quite happy with my life before being diagnosed. As you would think, obviously diet wise which you enjoyed, if you know, chocolates and things, unfortunately that’s, that’s practically gone out of the window...” (Anil)

“I don’t eat no lamb or sheep or red meat or anything like that. I eat chicken or something like that but I’m sick of the chickens. I love the lamb previously you know. You know, roasted everything. It is finished.” (Maahir)

“Just the food. The main thing you know, (is what I miss) the thing (favourite food) is lying there and you can’t (eat it)... ..” (Kiran)

The common perception among South Asians is that food is a source of health and strength. The restrictions with food were believed to bring a decline in their health status manifested as feeling weak and tired most of the time. These symptoms were perceived to be due to the inability to eat what they wanted rather than poor diabetic control. *“I had good health when I could eat what I wanted. I also looked strong but now am very weak and tired all the time.” (Haala)*

Dietary restrictions and regulations also imposed difficulties with their social lives since food and sweets were very central to any social event.

“When people come to invite me for Shadhi (weddings) and things like that they tell me, “We have got a special dish for you, vegetarian. So, please come.” My life is devastated. It is a full stop now.” (Maahir)

Psychological impact

The responses varied from frustration to anger, fear, loss of interest in self and uncertainty from having diabetes. Maahir articulates the psychological impact on him following a stroke related to his diabetes very clearly as follows:

“It (Life) is upside down. Everything has changed. I cannot drive. I miss travelling. I still try to go out to the nearby shops and that just for a walk and the way the people around look at you and feel sorry for you. I don’t like it. People in a car try to stop and offer me a lift and show sympathy. I hate it. I

have lost my independence. So, I don't like going out. Tell me, "What am I doing sitting here and waiting? Dying or what?" (Maahir)

He was frustrated and angry to the point of awaiting death since his travelling in particular which was reflective of his independence until the time of stroke had been affected. He also disliked the fact that people around him were trying to be sympathetic towards him since that seemed to reinforce his dependence on other people.

Kiran from India who loved his food expressed frustration very vividly in relation to the dietary restrictions imposed by diabetes as follows:

"Love it, you know. Still I feel craving but I can't. You see grapes, now I love it but ... you see It's the same with so many things which as you see... you know that dates, dates are good for you but the dietitian told me "No, you are not supposed to."

"This is the way. I brought the fish yesterday. I'll have to fry today and I say, "O God! Leave it today, then see tomorrow." Fish and chips you know, when I came here new, I was crazy if I passed the shop, I'll stop there, I'll eat it and then I'll go. Fry is no good for you. Fry is no good for you."

In the following quote, the woman expressed about her fear of death due to her diabetes related hypertension especially when she was on her own in the house for long periods of time while the rest of the family were working. She was wondering if the health services would be able to provide someone to stay with her in the house.

"The doctor is giving her the medication, giving her the advice what she needs to do but she is a bit worried because she has to stay in the house all day and all night till about three o' clock. In case if something happens and she dies. You know how she has got high blood pressure, if the pressure goes high and if

she faints and she has fainted, who is going to call a doctor?” (Interpreter of Chandana)

Galina, a woman from India was very upset about the fact that there was no cure for the diabetes – “*My daughter say, when we start this trouble, “Never cure, nothing”. I’m more upset all the time... ..the lady in the clinic, you know, she says, “Mrs. Galina, I can’t do nought.” Just all the time, I’m feeling too much, too much feeling, you know.”*

Impact on practising religion

In relation to religion, diabetes did get in the way of observing fasting and keeping hospital appointments during Ramadan, but that didn’t seem to stop individuals from practising their rituals or exercising their beliefs which was very central to their lives especially among the Muslim South Asians as evidenced in the following quotes.

“She tries and fasts during Ramadan as much as she can. She breaks her fast when she gets tired. She feels that the diabetes has not affected her very much with following her spiritual requirements.” (Husband of Haala)

“The only time, it (diabetes) might basically make a difference is if I was on Insulin then it could make a difference. But you can work around it. It doesn’t make any difference as far as practising my religion.” (Anil)

Social impact

Diabetes was seen to be affecting the South Asians’ social lives in terms of food, travel and time constraints for socialising since they were attending too many hospital appointments.

Hadarah from India shared that she couldn’t drive because of her peripheral neuropathy related to the diabetes and described that her social life came to a halt with

that – *“My social life is finished. I cannot go anywhere. I used to drive but I cannot now. All my time is spent in hospital appointments.”*

There were huge social implications for Maahir from Pakistan due to his loss of mobility with the stroke that was related to his diabetes. It had stripped him of his independence, ability to drive, time with his grand children and his status as the head of his extended family who live all over the UK and was actively involved in all the decision making process. He seemed to have lost his identity since he could not interact socially as before. He explicitly described the difficulties in his social life in the two following quotes:

“Well, previously, I like to do rambling, you know. Country walking, go hill walking. I like swimming. Took my children, when the children were young, I used to take them to the swimming baths, swimming with them, you know, and I also like you know, taking my grand kids out, children out, you know, driving. Going, the day I was off, in the morning we would make arrangements previously and I left, went by car for miles and miles you know, sight seeing, things like that and I miss terribly things like that because I cannot drive now. I am not allowed to drive. You know, it brought me right down.... Previously, I used to just jump in my own car, just went where I wanted. I’m handicapped, you know. I’m devastated, I am, I am, you know. I, I don’t know how most of these things happened to me. You know, I’ve lost my, I cannot drive. I’ve to rely on other people now. It’s bad that.”

“All my relatives live all over the UK and Scotland. I used to travel everywhere and used to be the Head of the family once upon a time but not anymore. It is terrible for someone who has been so active like me.... My life is devastated. It is a full stop now.”

There were also instances of people being resilient to all the social changes that came with the diabetes and carried on with their lives especially where it only involved food while visiting relatives or attending social events as described in the quote below.

“Sometimes when you eat things, you’ll have to be careful. Yesterday, I went to my friend’s house and then she had some sweets like jilebi (a sugary Indian sweet) but I didn’t take it because I thought, I shouldn’t. Then, I didn’t take but I had some other food.” (Madhur)

Impact on the family was not very significant as described by the participants except for changes with food habits in some instances as described earlier. They either made changes towards healthy eating as a family or carried on with the way they usually ate depending on what most of the family wanted or who had power and control over such issues within the family dynamics. Most people appreciated their family support in caring for their diabetes. In a few instances, the children had become pro active and were careful about their food or getting an annual review with their doctor perceiving that they too were vulnerable to have diabetes some time in the future.

“Like even the children worry about her a lot. Even the children are wary about what they eat. They don’t want to have Diabetes like their mother.” (Interpreter of Ila)

“The daughter believes that if it is diagnosed early, it only gets better and not worse and that it can be cured. So, since her mother’s diagnosis, she gets herself checked annually at her GP’s surgery in order to make sure that she picks it up early if she does get it.” (Field notes from interviews with Haala)

Sexual impact

Despite the fact that sexual dysfunction in men secondary to diabetes is widely documented, there was only one participant who brought it up very briefly during the interview. The researcher sharing the same ethnic background and being familiar with the taboos and social inhibitions around sexuality in general and the gender dynamics within the culture could not probe it any further. However, one of the practitioners mentioned that men usually were very concerned when they presented with symptoms

of sexual dysfunction during a consultation – *“The only complication that I find that gets more distressing is not renal failure or not hypertension, not peripheral vascular disease. It’s the sexual dysfunction in men. They get very disappointed. I have seen quite a lot of men who would rather get some help than for their renal failure. So, they are more concerned about that.” (Ian, Practitioner)*

Men seemed to want treatment for their sexual dysfunction but were unable to associate it with poor diabetic control – *“They would like to have some help for it with present medication rather than controlling it but you know. If I tell them it is due to Diabetes, they just say, “Oh! It is due to the diabetes, not because of the poor control.” They console themselves saying it is due to the diabetes, not because of the poor control.” (Ian, Practitioner)*

There was some positive impact described from having the diabetes but again noticeably it was from those participants who were educated, and had either had a health professional within the family or were involved in the health services themselves and were fluent in speaking English. It seemed to have empowered them with the knowledge to educate relatives about diabetes management and risk prevention.

“Positive, yeah. I’ve now become so much aware about the risks, about diabetes, not only me, my whole family have become aware about this. So we advise our family in Bangladesh what they should do and what they shouldn’t do.” (Madhur)

“Positively, I feel it’s eh...overall, I’m more aware of the consequences. I’m in a better position to give other people information and close relatives etc... And I now make some changes to my own life, so I would say it’s actually positive in that sense. You are in a much better position to advise other people.” (Anil)

Personal experience with diabetes related risks

This was another strong factor that influenced risk perception in this population. Maahir from Pakistan made changes that were required in his diabetes management after he had had a stroke and heart attack.

“They told me all the problems that could happen with my diabetes but I didn’t take it seriously at that time. When you are young, you don’t think about these things……. I started taking notice of the doctors, nurses and the dietician. Smoking in particular. I have tried to cut it right down. I used to smoke about twenty to twenty five a day and now I keep it at ten for two days. I find it difficult to give it up completely and need to have it after my meals. I take all my medicines and go for all my appointments.”

Participants were influenced by the past experience of caring for someone with diabetes which influenced their risk perception. Risks related to diabetes were not perceived seriously until they actually happened. Risks tend to be taken seriously only if was life threatening or seriously compromise one’s quality of life as shared by a female participant in the quote below:

“I didn’t take it (diabetes) very seriously. My husband had it and I looked after him. To tell you the truth, I didn’t even take my tablets sometimes because I wasn’t feeling unwell, you know. I took it seriously only when my doctors told me that my kidneys had failed because of my Diabetes.” (Hadarah from India)

Issues in relation to management of diabetes

The issues in relation to management of diabetes were hospital appointments and the use of medications with insulin in particular.

Hospital appointments

South Asians not attending hospital appointments regularly was a major issue with practitioners since this affected the continuity of care resulting in poor management of diabetes. It was perceived by the practitioners that people didn't attend hospital appointments due to travelling back and forth to their home country for long periods of time as discussed in the following chapter, the appointment not being sufficiently important or due to other priorities as described in the following quotes.

“They are very poor at keeping appointments, very poor, you know. Out of all the patients, all of our Diabetic patients it would be the Asian population that don't keep them. They just don't turn up or maybe because they feel it's not important or because they often they don't want to know, you know they don't want to know what the results are going to be or I don't know and it's very difficult, you know.” (Lyn, Practitioner)

The reasons for people missing hospital appointments were also multifactorial as another practitioner clearly explains –

“...even follow ups, we, we're going to have to prompt them but you know, “Tomorrow you've got a follow up appointment.” Whether that's (not keeping appointments) because they're comin' to a hospital, or whether that's because they don't read or write or speak our language and that we should and they're dependent on a family member to tell them and the family member who has forgot, and the, it's not that the patient isn't complyin'. It could be something as simple as that.” (Cheryl, Practitioner)

Lack of continuity for extended periods of time often resulted in having to start all over again to optimise care and diabetic control.

“...what we do sometimes find difficult is when people leaving, number of particularly older, more senior members of the family who actually eh... travel back and up to, up to three or six months and so often miss a lot of appointments.” (Malcolm, Practitioner)

“They default clinic, we lose them for a year. They go to the GP because they have recurrent infections. The GP refers them in as a new patient again and we try and start again on the cycle.” (Cheryl, Practitioner)

From the South Asians’ perspectives the reasons for not attending hospital appointments were some practical issues such as lack of memory, not having a family member to accompany them since that was very important to them, blood being drawn at each appointment, long hours of waiting at the clinic and the anxiety which elevates the blood pressure while waiting to see the doctor.

“Sometimes they forget, sometimes they don’t know, sometimes they haven’t got anybody to accompany them.” (Madhur)

“They take too much blood each time. I don’t like that. My arm gets very sore. My blood pressure is OK when I go to the GP but every time I go to the clinic, it goes very high. I don’t know why. Sometimes you have to wait in the clinic for a very long time and sitting in the clinic, I feel very tired.” (Haala)

Haala, has also been reluctant to start herself on Insulin for several years despite extremely poor diabetic control. The need for starting insulin had been reinforced during each appointment and that’s probably also one of the reasons as to why she was not very keen on her hospital appointments. She was convinced that insulin was not good for her and the doctors were wrong as described in the following quote –

“I don't want the insulin because they are always telling me that insulin is good for me but insulin is no good. It makes the sugars go very high.” (Haala)

Medication – Patients with diabetes are treated either with insulin or oral hypoglycaemic agents for diabetic control. Issues around medications involved discontinuation of medications without consulting a professional for a number of reasons such as side effects of drugs, lack of information and their choice to adhere with religious requirements.

In relation to the impact of side effects of the drugs, people tend to feel increasingly unwell with some of the side effects than they have been with their diabetes and hence discontinue the tablets associating it with the reasons for being unwell. This is described by two practitioners in the quotes below and in the third quote, by the husband of Haala with diabetes.

“With their medication, you find that when they come back to clinic that may be's they haven't been taking their tablets or they'll stop taking their tablets and they'll freely admit they've stopped taking their tablets for often really probably had nothing to do with their Diabetes. They'll eh.. you know, they might be on Metformin to give an example, and they'll say they felt all shaky and they wa... their blood sugars were low. So, they just stop taking their Metformin.” (Cheryl, Practitioner)

“Some people just go away and they don't take treatment at all saying that they have no ill effect and they feel ill when they take the treatment. The main thing they stop the treatment is from oral hypoglycaemics when they have any side effect. They say, “I was well before seeing the doctor but now I'm having terrible problems. I have tummy upset, I have diarrhoea”. Whatever it is, they stop the treatment and they you know, do not return until they have a complication.” (Zoe, Practitioner)

“She takes the tablets that have been prescribed and discontinued one of them because she lost her appetite with it. She did this on her own without consulting the doctor.” (Husband of Haala)

People also lacked an adequate explanation or understanding of the possible side effects of medication. They didn't seem to understand that their medications needed to be continued in the long term either due to lack of information from the professionals or due to the side effects of the drugs.

“...it's also because you've decided for whatever reason, you don't need your diabetic tablets anymore perhaps because they give you side effects which haven't been properly explained or you didn't understand the explanation of why you're taking it or that sort of issue.” (Malcolm, Practitioner)

People change the dosage of medications around to suit their religious needs like fasting during Ramadan without consulting the doctor because of their strong religious convictions, based on their home glucose monitoring or the amount of sweets they have eaten.

“...they (doctors) will say, “Don't fast and have the medicines. So, he changes his own medication. He says, “Doctors can't give anybody life. They just help you but it is Allah who gives you life.” (Interpreter of Baqeer)

Some of the drugs (Aspirin/ Simvastatin) that are prescribed for people with diabetes are for long term risk prevention and the lack of visibility of those probable risks makes it difficult for practitioners to explain the need for regularity with those medications. The number of tablets one has to take everyday also increases with the prophylactic management of the disease and requires frequent monitoring (blood tests) to ensure optimal control. People find this difficult and choose to either skip a few drugs or discontinue treatment since the risks aren't visible, immediate or palpable.

The following quote illustrates this very clearly –

“I think it’s sometimes difficult to explain the prophylactic nature of some of these drugs particularly when you are talking about say, Aspirin and Simvastatin which have large prophylactic role and you’re treating risk factors and that also this tendency, that if for example, and patients are not keen on blood monitoring...” (Malcolm, Practitioner)

Insulin

The other major issue that came in the way of risk perception related to diabetes was around treatment with insulin. The practitioners were keen to start people on Insulin when the diabetic control was suboptimal for long periods of time and posing a threat with long term and life threatening complications. They often found it challenging to convince people with the need for Insulin for a number of reasons such as needle phobia, dislike of having to take injections everyday, apprehension with having to acquire the required skills to do it and the lack of understanding of the impending risks as described in the following quotes:

“...transferring South Asian females on to Insulin, and males you can ... there’s lots of barriers. They do not like giving injections. Females, ... often want ... a third party to give the injection for them...” (Cheryl, Practitioner)

“100% of the people do not want to go on Insulin. And people on Insulin want to say every time they come, “Can I not go back on my tablet?” So, here we find very difficult to control, so even on Type 2 we use Insulin now both insulin and oral hypoglycaemics which they don’t understand. So, people usually when they are suggested insulin, they avoid it as much as they can.” (Ian, Practitioner)

There were also instances where men especially did not want to have insulin since it would affect their jobs and eventually their role as providers for their families. Most

older South Asian men in the study from Pakistan were taxi drivers and if they were to go on insulin it could adversely affect their jobs due to the legal requirements with their driving licenses as explained by a practitioner –

“We do have an awful lot of problems gettin’ patients to accept that they do need Insulin. Because they feel that if they go on to Insulin, you know, there’s no way back. That’s it. That’s the beginnin’ and the end and they resist it. They resist it for lots of reasons. It could be to do with employment and we have had a few where it’s been employment and drivin’ has been an issue.” (Cheryl, Practitioner)

Women in particular, from the South Asian background had a lot of reluctance to start themselves on Insulin. They expressed feelings of anger and resentment towards having to take insulin rather than perceiving it to be helpful towards their diabetic control long term. Saabira, a woman from India articulates her response to starting insulin very explicitly in the quote below:

“No. I not want to do that. Doctor say, “You have to; You have to do that.” I really angry with doctor. I not do that. He give a pen (Insulin pen) straightaway.” (Saabira)

She also went on to explain that it was her fear of needles that caused the reluctance.

“I’m frightened. Needle everywhere. Aye”.

Haala, from Bangladesh had been advised to start herself on insulin for a few years but didn’t even want to consider it because of her fear of needles and having to inject herself –

“It has been suggested for a few years now that she needs to go on insulin since her glycaemic control is very poor but Haala doesn’t even want it mentioned to her. She is on the maximum dose of Oral Hypoglycaemic agents

but is absolutely petrified at the thought of having to inject herself into her abdomen everyday and hence doesn't want to even consider the option. (She closed her eyes tight at this point and waved both her hands gesturing that she didn't want it.)" (Field notes from interviewing Haala)

They also expressed that there wasn't an element of choice with having to start insulin since it was mostly decided by the professionals without them being given much of an option.

"They gave it to her. She had to take it. She didn't have the choice. Obviously she didn't want to take it." (Interpreter of Ila)

Women with past experience of having seen a family member on insulin were reluctant to start insulin since they had seen how it had affected the person they loved (as they perceived) and hence chose for themselves not to be in the same situation. In the following quote, Haala from Bangladesh shared that despite being on insulin her mother's diabetes wasn't well controlled and hence decided that it wouldn't do her any good either.

"I have seen my mother taking insulin for years now and she goes very dizzy and confused at times (having severe hypo attacks); her body looks swollen all the time and her sugars are always high. I have to carry it everywhere I go especially to Pakistan and it is very hot there. Insulin is no good."

This also makes it clear that her understanding of the nature of the disease and the lifestyle changes that needed to go along with the medication were limited. She even avoided hospital appointments since insulin was suggested to her each time she went to the hospital. She was convinced that insulin wasn't good for her and rather than being able to see the need for having the insulin, she sought to pray that she would meet a doctor who wouldn't prescribe insulin as mentioned in the following quote.

“When we go to the clinic, we pray that we will get a good doctor who will not force me to take insulin. “I haven’t tried explaining why I don’t want the insulin because they are always telling me that insulin is good for me but insulin is no good. It makes the sugars go very high.” (Haala)

Maasma from Pakistan expressed that she disliked having insulin for the following reason

“It bothers me because my mother in law and my step mother were having them you know. I saw her when she was putting them on you know, I saw how she went through with that. She has died now anyway. That’s why I don’t like.”

Lack of immediacy & visibility

Inability to make the connection between diabetes and its long term implications was another major issue from within the data that was collected from the Health Development Workers in the focus group interviews. Some people didn’t seem to believe that diabetes could impose serious long term risks such as hypertension, stroke and heart disease since all the pathophysiological changes that lead to risks are gradual but progressive and hence non imminent, internal and hence invisible as in the following quotes.

“Like you know, one lady she questioned, “How, how is it with Diabetes? You said, related with pancreas, this and that and it’s about sugar, how it happens with I’ll get stroke?” They don’t believe.” (Hita, Focus group)

“There are few people with kidney disease and some people have heart attacks but there’s nobody like that’s gone blind or had an amputation or There’s one or two who has had a stroke as well. So, I don’t think they see that as it being due to Diabetes...” (Purva, Focus group)

“Because, another of my women, have gone to develop high blood pressure but I don’t think for one minute they think it’s because they’ve got Diabetes. Even if you try and explain that, I don’t think they believe.” (Juhi, Focus group)

Symptoms of some of the risks associated with having diabetes such as diminished vision or sensation on the hands and feet were connected with getting old and hence they didn’t seem to understand that they were related to poorly controlled or long standing diabetes –

“People actually under estimate the complications and what can happen until you see somebody and it’s, it’s so hidden and it’s not a sudden change. It’s over time you, you find that that your sensations are reduced, eyesight etc.. are reduced . It’s over a time period and people don’t actually connect back with it being Diabetes out of control. So, may be they think “it’s just old age anyway that’s creeping up.” (Dhiren, Focus group)

Another interesting feature that emerged about the way people perceived long term risks was influenced by the lack of visibility of the proposed risk and the immediacy of it from the practitioners’ point of view. As one practitioner stated – *“When they come to clinic, Diabetes isn’t their main focus. They’ll focus on all their other pains and which may or may not have a bearing been you know, as a result of their Diabetes. But it isn’t their Diabetes. They don’t want to make changes there, because they cannot actually, see it, feel it. For although, a lot of what they’re experiencing or is a result of poor control.” (Lyn, Practitioner)*

The fact that symptoms related to the long term risks with diabetes were not easily visualised, felt or palpable seemed to affect the way risks were perceived.

“It seems that it goes through one ear and goes out through the other one because it is cultural that they only, if they’ve got pain, they are here. This is

something which doesn't have a direct you know, symptom which they think, "Why should we bother?" – (Ian, Practitioner)

Key Summary

Understanding of diabetes as an illness with serious long term risks was very limited. South Asians believed that the cold weather, lack of sunshine and lack of fresh traditional food predisposed them to diabetes. This also led them to believe that the diabetes disappeared and hence discontinued medications when they travelled back to their country of origin. There were instances where South Asians identified life style factors and lack of Insulin as being responsible for their diabetes. Interestingly, all these participants (5 out of 20) had a family member as a health care professional.

The commonality of diabetes (diabetes in almost every immigrant South Asian household) negated the seriousness of diabetes related risks. The lack of immediacy and the concealed nature of the proposed risks (renal failure, coronary heart disease etc) compounded this even further. South Asians tend to discontinue their medication due to their side effects. The side effects with the drugs were immediate, visible and palpable (eg. Diarrhoea with using Metformin) as against the invisible benefits of taking prophylactic drugs (Antihypertensives / Statins) towards Stroke prevention long term. Issues in relation to diabetes management were around having insulin for optimal diabetic control. South Asian women in particular were resistant towards having insulin prescribed for a number of reasons. Having insulin was considered as a riskier option (immediacy) versus preventing long term risks with optimal diabetic control (non visibility of the benefits proposed).

The impact having of diabetes ranged across physical, psychological, social, spiritual and sexual aspects of their lives. However, risks were perceived to be serious only when they were personally affected by the proposed risks (Renal failure as in the case of Hadarah and Stroke in the case of Maahir).

Conclusion

Risk perception is an important aspect of decision making under risk and uncertainty that tends to vary widely between individuals (Bontempo et al., 1997). Health related lifestyles and risk prevention are influenced by a number of personal, socio cultural and other factors. Personal factors such as understanding of diabetes, perceptions on the severity of one's diabetes, the various impact (physical, psychological, social, loss of independence, personal intrusion and the impact on the practice of religion), personal or past experience of caring for someone with diabetes, the lack of immediacy and visibility of the risks proposed, significantly influenced the way risks were perceived by older South Asians with Type 2 diabetes. Most of these personal factors operated within the cognitive domain that resulted in risk awareness which subsequently determined their health behaviour in relation to diabetes management in general and engaging with diabetes related risks in particular.

CHAPTER: 6

RESULTS

THE AFFECTIVE DOMAIN

(Socio cultural and religious factors influencing Risk perception)

This section deals with the socio cultural and religious factors among South Asians such as spirituality, culture, gender, perceptions on ageing, family dynamics, hospitality and travel back to their country of origin and their influence on risk perception. Culture has been described as ‘A set of guidelines that is inherited by an individual as a member of the particular society that tells them how to view the world, how to experience it emotionally and how to respond in it, its relation to other people, to supernatural forces or gods and to natural environment’ (Helman, 2001). Culture has also been described as an ‘inherited lens’ (Pawa, 2003) that enables an individual to perceive and understand the world that they live in. Anthropological analysis accepts that there are three levels of cultural behaviour: what people say they do, what they are actually observed to do, and the underlying belief system which drives that behaviour (Hall, 1977). At one level, culture is visible externally in terms of rituals, festivals and traditional clothes that are worn that which is observable and often not very resistance to change. On another level, it also functions and is practised at a deeper level with stability which is often difficult to be perceived or changed. This level seems to underpin rules and beliefs known to the individuals within the cultural group but not very often shared with people outside the culture (Pawa, 2003).

Social and cultural perspectives are becoming increasingly important in the field of risk research. The Cultural Theory (Douglas et al., 1982) describes the impact of values and cultural settings on the perception of risks. The theory emphasises that risk perception on environmental and social issues are socially and culturally framed (Rippl, 2002). Individuals are embedded in a social structure within a social context that shapes their values, attitudes and worldviews (Douglas et al., 1982).

Understanding and information on risk is a cognitive process within an individual. Since the individual lives in a social context that influences values and beliefs, ‘the socialised cognitive processes act as filters in the evaluation of information about risks’ (Stern et al., 1995). Based on the cultural theory, the predictors of risk perception are not just the individual cognitive processes such as threats to health but also their socio cultural beliefs and influences that determine one’s risk perception (Dake, 1992). Thus, an individual’s cultural background has a significant influence on their beliefs, values, perceptions, practices, rituals, food habits and attitudes towards health and illness.

In this context, it was observed from the data that there were several issues such as the role of family, family dynamics, ageing, food and hospitality addressed within the culture that tends to be quite varied and heterogeneous even within the South Asian communities.

The socio cultural and religious factors represent the affective domain and refer to normative beliefs in the Theory of Planned behaviour. Normative beliefs result in perceived social pressure (Ajzen, 2002a). The normative beliefs determine subjective norms and the socially expected mode of conduct (Ajzen, 1991). The socio cultural and religious expectations within the South Asian community have a bearing on how people engage with risks related to diabetes fulfilling those socio cultural and religious requirements. Similar to risks that result from less than ideal diabetes management, the normative beliefs lead to perceptions of risks that could result from the lack of fulfilling socio cultural or religious requirements that are expected. For instance, turning down sweets that are offered while visiting someone which is symbolic of South Asian hospitality could lead to the risk of social offence. Eating those sweets would predispose them to impaired glycaemic control. This also predisposes the South Asians with diabetes having to choose between the risks involved which in turn results in ranking the risks. South Asians mostly seem averse to risks that were visible and imminent (social risks) when compared to those risks that were concealed and non imminent (risks related to diabetes). The socio cultural and religious beliefs largely operated within the affective domain and facilitated choices in engaging with risks.

Religion and Spirituality

People from within the South Asian communities especially from Pakistan / Bangladesh tend to view religion as the most supreme part of their lives when compared to health or even their families. There seems to be a strong notion that adherence to their religious requirements far outweighs everything else including caring for their diabetes as evidenced by the following quote.

“Well, we have the different religious grouping, and one of the most striking things that are practised here are festivals such as Ramadan. And that and then the Hajj. And that really pertains to our Moslem South Asians because not all of them are Moslems but the groups that come to mind most are the... are the groups that are practising their religion and it is more important to them to practice their religion than to worry about their Diabetes care.”
(Miranda, Practitioner)

Religious requirements during Ramadan were considered to be far more vital to the extent of shelving all other duties or responsibilities as clearly articulated in the quote below. Apart from their regular prayers that were said five times a day usually, Ramadan was a time that was dedicated to getting closer to their God and religion which was the essence of their faith and purpose for living. Staying in the mosque for those ten days was a way of symbolising their dissociation with worldly responsibilities and renewing themselves spiritually without any distraction which was deemed very important especially for men. Since the women are not allowed into the mosque for social reasons such as mingling with other men, they were expected to stay indoors and perform their religious duties. This also meant that they risked missing hospital appointments for their diabetes care during that time.

“Basically what happens is in the last ten days of Ramadan, people take their holidays and they will then go to the mosque and they will stay there day and night. They will say their normal prayers and after that it’s all reading the Quran or reading the translations and trying to get more and more familiar

with their religion and that's their whole point for those last ten days really. If you can't do that, you can go even for one day or two days or whatever, whatever time you can spare basically. And you sit in the mosque and it's just a way of actually removing yourself from everyday duties so that you can concentrate more on your religion and what it's all about. Otherwise, people will be generally saying their prayers. Women will be saying their prayers in their home and then as soon as they finish, they know that they don't have to prepare any meals during the afternoon. So, that's when they will be sitting in their homes and reading their Quran etc.” (Anil)

Men seemed to be a lot more determined about fulfilling their religious requirements during Ramadan. Women expressed that they would have preferred to observe fasting and it caused unhappiness when they were unable to do so.

“She felt very unhappy that she couldn't observe the fasting and as a Muslim, it is a must to observe fasting.” (Interpreter of Rabia)

Going on “Hajj”, a pilgrimage was another priority for the South Asians who were Muslims. Hajj has a strong religious significance and involves a series of ritual acts and religious restrictions symbolising the solidarity with Muslims worldwide. Pilgrims are required to walk very extensively on uneven terrains with physical hardships to perform their acts of faith. The rituals have a deep psychological significance with a profound spiritual experience. A Muslim believer is expected to go on this pilgrimage at least once in his or her life time. Those who complete the Hajj are considered to have had one of the greatest spiritual experiences.

People perceived that their diabetes seemed to be better controlled despite not taking medication as advised during the Hajj. The reasons for this control were perceived differently by practitioners as against the individual with diabetes. Practitioners felt that the extent of physical activity during the Hajj seemed to do their blood sugars good whilst the South Asians with diabetes perceived it from being due to performing their religious duties and the satisfaction that resulted from it.

“Some people they come especially to get their medication and they seek help. Some people do not seek help but I’ve never seen any major problem with Diabetes. It was out of control for some people but it all slightly gets better. They’re eating and they also walk quite a lot when they go there. So, the control improves for some people.” (Ian, Practitioner)

“May be, I went for this Hajj, you know, this pilgrimage to Mecca in January. May be that is a bit of satisfaction, I don’t know. So... I didn’t use any medicine there.” (Sa’ood)

There was also a fatalistic attitude towards having diabetes and people seemed to resign to that belief with a sense of powerlessness as confirmed by both South Asians and practitioners.

“I think the response varies but I think unfortunately, quite frequently there can be a fear. Umm... and certain amount of hopelessness associated that it’s a little bit fatalistic approach in some people rather than as we would hope to that they can take control but can manage it, from that.” (Zoe, Practitioner)

“Actually we don’t believe in these things. You know, how in this country they do believe like I should have been in good diet from childhood then I might not be getting it. We don’t believe in that. Our fate is totally different. It’s like you think, Allah decided to give you the illness, He will. No matter how well you are or how healthy you are.” (Interpreter of Chandana)

With their personal faith, there was a tendency to hold God as being responsible for their illness or shift responsibility as evidenced by the data from the focus group interviews with the ethnic Health Development Workers. Acknowledgement that the individual’s life style may have been responsible in some way to have a preventive influence was very limited.

“Another change is I often debate with my clients, you know, their belief. If you are believing your God and then at the end, you know, you know, you’re doin’ everything right and then you just start blaming on Him. You know, the God all the time or that God willing this happened to me and I had to, I mean, you don’t, you don’t see yourself where you have lot of issues about yourself which (Laughs) you mismanagement all these years. You know, when like smoking, God didn’t say, “You smoke” and then your heart has become you know, where the stage is, you can’t carry on with it. So, often that happens, you know, people blaming.” (Samir, Focus group)

Reliance and dependence on their spiritual beliefs and values alone to manage their diabetes or any illness was controversial. There was an instance of fasting during Ramadan without consulting their doctors since he believed that it was Allah who gave him life and therefore his dependence was on Allah and not his doctors who cared for his diabetes as described in the quote below. Religion was very predominant in his life and he strongly believed that his life was in God’s hands.

“No, because they (doctors) will say, “Don’t fast and have the medicines. Doctors can’t give anybody life. They just help you but it is Allah who gives you life.” (Interpreter of Baqueer)

The Quran seems to actually recommend that that they used both prayer and medicines when they had an illness rather than ignore or neglect the medical help that was available.

“There’s two things... One which is prayer. Now, in Arabic, we call that Doa. So, you’re praying, right. And there’s another word which is? Doac which is medicine. Right. In actual fact, we should be concentrating on prayer and medicine. So, it is all, it’s the same word. Now, slightly different. And some people will say, “You need both. You need prayer and you need the medicine.” So, if you actually just think with prayer, and God says, “I’ve already given you the knowledge that if you take antibiotics you’ll be cured

from this particular problem that you have”, and you just sit back and say, “I’m just going to pray. If God wants me to recover, I’m going to recover.” God has also told you that you could actually use the medicine in there and there’s a lot of things in there.” (Dhiren, Focus group)

Religion and religious beliefs were held important by the South Asians who originated from India but it was practised to the extent of visiting the local temple regularly or wearing images of gods on their body. Fasting wasn’t mentioned by the Indian participants in any of the interviews and they seemed to perceive that practising their religion didn’t influence the way they managed their diabetes or their understanding of related risks.

“You see as I am a Sikh, I’m not a rigid fanatic but and you see, there are so many things... you don’t cut the beard this and that. I did everything but I don’t drink or I don’t smoke but I believe in religion. And I go to the Sikh temple whenever I can. I must go once or twice a week and I do the same (go to the temple), you know.” (Kiran)

“I was told that my kidneys failed because of my Diabetes. I thank God that my kidney is working again. I take all my medicines regularly. I believe in God and I’m very religious. My son took me to the temple last Friday you know. I wear all the images of my Gods on me. (Showed me some pendants of her Gods which she was wearing around her neck).” (Hadarah)

Family Dynamics

Family was a significant priority among South Asians and people tend to live in joint families with multigenerational and extended family members. South Asians often valued family support in caring for their diabetes and perceptions of support ranged from being accompanied for hospital appointments, a family member interpreting during a medical consultation, being reminded to take their medication and children moving in to live with them as evidenced from the following quotes.

*“My family. No. No. My daughter no mind at all. She take me to hospital... ..”
(Galina)*

“Her family, daughters, they, they are thinking that it is now their responsibility to look after their mother and they try to teach her, “Don’t do this, Don’t do this,” means, try to control her diet, medications they are looking after.” (Interpreter of Galina)

“Particularly the older women who attend are often matriarchs or grandmothers and will attend with younger family members.” (Malcolm, Practitioner).

The following quote clearly depicts the extent to which family support is made available to someone with diabetes. *“You know, I try to carry her through this (Diabetes). It’s like having two hands. If one doesn’t work, the other suffers. So, I try to help as much as possible.” (Husband of Haala)*

The family dynamics (with the concept of extended family still being widely practised) varied significantly to the Western context (where nuclear family is the concept). Decisions regarding diabetes management, especially in relation to food, seemed to be influenced by perceptions of agency (individual versus family), power or control that the individual had within the family, gender and social expectations.

“It depends on the status within the family and the influence they have on changing from that... .. it may be that it’s an elderly lady who is living with their son and daughter in law eh... and she hasn’t got quite sufficient or doesn’t feel she can put on to her daughter in law when she is making meals to buy a different type of oil or to use less of it for the children and I think there are issues.” (Zoe, Practitioner)

“With ladies, they make food for the family, what they are making using lots of ghee, this and that. They don’t make for themselves. They are finding difficulty. Traditional meal, they are making. So, that’s the problem for them.” (Hita, Focus group)

In another family, the wife was diagnosed to have diabetes six months prior to the husband and the family’s dietary pattern changed only after the husband was diagnosed to have diabetes along with a cardiac problem as interpreted in the following quote.

“The doctors told him that the diet he has had with too much oil has gone to the arteries and stuck to the arteries. That has narrowed the arteries a bit. They changed the amount of oil they were using. They don’t use ghee. They try to eat more fruits and vegetables. They changed all this after he was diagnosed to have Diabetes.” (Interpreter of Maahir)

In the example above, the wife was still doing all the cooking for the family but still had the ability to change the dietary pattern only after the husband’s health situation required it rather than her own.

Practitioners expressed that provision of information or knowledge alone didn’t seem to be the solution in preventing risks related to diabetes since making the life style changes that were required based on the information provided largely depended on their family dynamics. The life style related issues seemed to be more complex within the family dynamics in South Asian families.

“I think there is something more complicated going on in the family dynamics that just giving them knowledge that you could have badly controlled Diabetes which leads to complications in the future isn’t quite good enough.” (Miranda, Practitioner)

The older South Asians from Bangladesh preferred not to bring their women family members into the UK since they perceived that the western culture might adversely influence them. So, the wives were often left behind in Bangladesh to raise the family on their own till their husbands felt that it was appropriate for them to come and live in the UK. Apart from having to face the challenges and coping with the stress of raising children on their own, women expressed that it was difficult to care for their diabetes sufficiently in such an environment.

Chandana from Bangladesh shared during the interviews as to how part of her family (children) were left behind in Bangladesh as desired by her husband and that she often wished that her daughter was with her in the UK primarily to assist her with the responsibilities in the house which she disliked and was unable to perform because of her fatigue. The woman's role within the Bangladeshi community is mostly to stay indoors and care for the family's needs. However, this trend seems to be changing with the younger generation.

“Like if you have a daughter, she will be in the house, a son, he'll be out. Husband, he's out. So, if you have a daughter she will be in the house, she will be looking after you.” (Interpreter of Chandana)

Food – A Social Event

The South Asians' meal pattern mostly consists of rice or wheat in the form of “chappathis” with curries made using a lot of oil or butter and vegetable or meat. It is a sign of hospitality in the South Asian culture to offer something to eat or drink (usually tea / coffee) when someone visits their home. Offering food or a drink that is sugary and sweet is symbolic of a welcoming gesture and hence tea and coffee are usually prepared with a lot of milk and sugar. Desserts are mostly fried and tend to be very sweet. Issues such as power and control strongly influenced health care decisions and the dietary pattern that were adopted within the family. Cooking was usually done by the women and there were instances of the individual with diabetes cooking what

the family preferred mostly despite it being unhealthy or harmful in the management of diabetes.

“They are like, the female in the house. They (women) are doin’ the cookin’. So, and they’re doin’ the cookin’ for what the majority of the family want.”
(Cheryl, Practitioner)

Food is a social event and often involves extended family members and other relatives. Saabira, a woman from India shared that three of her children were married and had their own homes but they all came to meet up everyday in her house for a meal and she cooked the meal for the entire family.

Family gatherings were regularly centred around a main meal of the day regularly which is again very central to the South Asian culture.

“...although their culture is wrapped or it appears to be wrapped around their family meal times and food and you know, there is a lot of kind of eating times and the diet seems to be quite a high fat diet. So, I know it is quite difficult to change because things have been handed down from generation to generation it is quite difficult to eh sometimes Asian people to think differently about the way to eat and the timings.” (Lyn, Practitioner)

This was observed to come in the way of one’s diabetes management by the practitioners.

“Although they seem to have a long spell sort of like from breakfast through till about three o’ clock without any food and then they’ll have lots of meals after that. So, I think that’s that umm... quite difficult because that doesn’t help the weight and it’s the high fat food they are eating. And that’s all tied up with their culture Their family values, I think.” (Lyn, Practitioner)

“...from my understanding sort of the family and how things are organised, food is a very social occasion. Umm... and from the patients I've looked after, it tends to be quite late at night, in quite large amounts, Umm.. with huge spaces between the food which is exactly in Type 2 Diabetes what we wouldn't want people to be doing.” (Emma, Practitioner)

The family dynamics in relation to dietary pattern and food habits were quite complex and it was noticed that if changes were made as required with food habits it was either made by the whole family or not at all since food has a lot of social significance among South Asians.

“The problem that I have sometimes come across is that when they are diabetic, you want to try and change somebody's eating habits and try and eat healthily, it's either done as a family, family thing and everybody changes or it's not done at all. It's very rarely that you come across someone who will say, oh well, they cook for me specially.” (Dhiren, Focus group)

There were also examples where the family were extensively supportive and positive with the changes that were required to prevent long term risks for the individual with diabetes.

“In fact, in our house nowadays we don't make so much sweet. And we try to eat more vegetables and fish and meat. They are very supportive to me. They don't eat what I don't take.” (Madhur)

“Long time ago, we stopped in the eighties I think, we stopped using butter, pure ghee. We moved to using vegetable oil and then we changed to corn oil. Now, we use olive or sunflower oil. I told my wife that we needed to change and the whole family changed. They were all happy to change.” (Daanaa)

Interestingly in both the above quotes, there were medical professionals within the family who were positive and supportive towards the changes that were required to be made with the family's dietary pattern.

Hospitality

Food being a social event symbolising hospitality and love within the South Asian culture, there were dilemmas as to whether cutting down someone's diet or restricting what they ate was perceived as lack of love towards that individual with diabetes.

"I note the elder, the elder women don't cook and so they are having their food given to them. Now food is an expression of, of love I suppose, and if they cut back with food does that show that they don't love them? I don't know.."
(Miranda, Practitioner)

"Husband sometimes, doesn't stop her to eat. He feels that by stopping her, he feels he is being rude." (Interpreter of Saabira)

Hospitality was also symbolised by way of offering food or drinks to anyone who was visiting a South Asian home and it was considered an offence or being impolite not to comply. It was considered important to comply with the social demands rather than an individual's preference.

"You can't say, I mean when they make tea, I say, "No sugar," but people bring coke (Coco Cola) and this and that. Sometimes, I don't take but sometimes I do take a little bit. But I think when I go there, and I test my sugars it is always higher than here." (Daanaa)

"When I go to weddings and that you know. When the food comes, well sometimes you have it and sometimes you think about it and say, "I shouldn't have this", you know. But you have to have a little bit. That's what happens you know. Some ladies who sit beside you say, "Have it, have it", you know."
(Maasma)

Perceptions on Ageing

Perceptions on ageing varied and were influenced by cultural differences across an individual's life span, belief in fate, their relevance to the family's needs and interests and the accomplishment of their "duties" in terms of their children's education, marriage, arrival of grandchildren etc. With the average life expectancy being sixty five, South Asians tend to regard people in their fifties as "old" as affirmed in the quote below.

"The one important thing culturally with them is, anybody after the age of forty, forty five, they call them old people and tell me, "My mother is very old." "How old is she?" "Oh! She is forty nine." And I'm sitting thinking, "I'm fifty nine, you know. It's time for me to be dead and buried according to them. They all class them and as soon as they pass the age of 45. Fifty means, they are very old. "My mother is very old." That is culturally, we have to look at it. So, anybody expects some diseases and I've never seen anybody losing weight after that age." (Ian, Practitioner)

The fact that Type 2 diabetes is usually seen in older adults seemed to have a significant bearing on how long term risks were perceived since South Asians considered themselves to be old when they were in their fifties and didn't find it relevant to make drastic life style changes as recommended.

"Once again it's the fact that when you're a Type 2 diabetic, it's at a later stage in your life. I think that's a big factor. If you were a Type 1 diabetic at the age of what, whatever and then you've got another forty, fifty years to live possibly. You would be in a position to say, "Well, I better make some changes if I want to live that long." But if you've already come to about fifty and the average age in the Asian population is about sixty five, seventy maximum, you feel you're nearly there already. So, what's the point of making such drastic changes? (Anil)

“Overall, people put a lot of things down to fate anyway especially when it comes to age, how long you’re going to live. And if you’ve lived a fairly reasonable life, you know you don’t bother; you don’t take that much of a consideration, really.” (Anil)

“At this stage, I’m really at the end of it now. I’m in my sixties. If I was younger, I would say, “Yes, business first.” (Daanaa)

Meaning of Health

Health is usually viewed as absence of family problems, financial sufficiency, absence of illness, happiness and good housing with all the physical facilities required. Most South Asians seemed to want good health and be able to perform their “duties”.

“I feel it’s most people have a hope that they have good health daily work and daily whether you are religious or you are not, you still have to have the health to actually perform your duties. Umm.. Most people generally, when we see them would want good health.” (Dhiren, Focus group)

Accessing services for health care needs depended upon factors such as literacy, awareness, age and other priorities among South Asians as clearly explained by a health development worker during the focus group interviews.

“So, people are quite aware of their health depending on the age group that you’re going for and whether they are actually going to go to the chemist and buy some over the counter medication or going to the GP, that’s a different matter. And then, if you’ve got work commitments, you can’t actually go to the GP nor have the time. Or if you’ve got a bit more knowledge, you can actually, you are aware that the pharmacist is in a position to advise you, on general health and medication that is available. People are aware of their health but it’s just actually using the facilities. But it varies across the board depending

on what age you are as to how much facility you are or not going to use. ”
(Dhiren, Focus group)

As stated by Purva during the focus group interviews, health seems to be high on their agenda among South Asians in general but quite often other priorities such as family, children and their business take precedence over their health. Adherence to all the recommended life style changes such as exercises, involves input in terms of time which would adversely affect their business and income with implications for their families and financial stability. So, health is viewed as something ‘here and now’ and how they feel day to day rather than be worried about long term risks that also would possibly have adverse effects. It is not always the lack of knowledge about what is good for managing their diabetes but the immediacy of other pressures such as their business demand their time and attention probably also because they don’t feel particularly unwell or incapacitated with their diabetes.

“I think there’s a whole different lot of what people believe and what they feel about their health depending on their background, where they come from, what sort of job they’ve got, what sort of family they’ve got but I think across the range if you look to the business end, some people it’s not even just that they want to spend that time in their businesses. If they don’t spend that time in their business, their business isn’t going to work and that’s going to create them more problems. So, I know some people who have got Diabetes, who they know, they should go to the gym, they should do some proper exercises, they should eat well but actually their priority is “I’ve got to get up; Get to work; Get this business done…… And I must get to the supplier before such a time; Haven’t got time to stop and eat.” So, they know mentally that it’s good for them but they can’t do it.” (Purva, Focus group)

Responsibilities and constraints in the work place such as restaurants where men worked mostly with irregular meal timings seemed to interfere with the way they managed their diabetes.

“... there’s another end of where people who are restaurant workers who May be have less information about what’s good for their health but still have little control over, you know, they have to go to work at these times, they have to be working in the kitchen, they can’t just decide “O! I need a break now for a snack now for my Diabetes.” You know, so I think lot’s of things that people don’t have control over but the reason I do think like the people I’ve worked with, even, even people who people might say are like lower socio economic groups.” (Purva, Focus group)

Health was considered to be the foremost in the order of priority and central to an individual’s life especially among the non Muslim participants. *“People say money first, but I say health is first. If you have good health, you can do everything. If health is bad, what do you do? If health is alright, you can do the job, make some money, go anywhere, enjoy yourself, you are independent, yeah? Health is first.” (Abhaya)*

Yet, interestingly having diabetes was not considered as being unhealthy or cause concern to Abhaya because he believed that being unhealthy is due to one’s bad luck which he didn’t have control over. Despite being desirous of good health, the fatalistic attitude towards life and all the life events had a major influence on how health is perceived. It was also perceived that it was important to be happy, independent and not worry in order to stay healthy.

“....if you get any trouble anywhere it is due to bad luck. It depends on the luck you know, good health, bad health where you are. Anytime, I never worry this way. Some people say, “Oh dear, Oh dear.” I think about it for four or five minutes and after that I say, “Never mind, what is in the luck is what will happen.” (Abhaya)

It was also observed from the following quotes that the South Asians often wanted good health for their family and children in particular.

“To me, families see health as a priority and they are very keen that their children Ummm... have good health and you know, have the best.... Just like any family they're very keen that people have the, their their children have the best they can including health.” (Purva, Focus group)

“.....I tend to use that tact that you know, “If this was your children, you would though never miss the medication because you would always, if the child needed medication three times a day, you would make sure they got it. So, why isn't that priority for you? And they just smile.” (Emma, Practitioner)

Travelling back to their country of origin (Holidays)

Holidays usually meant going back to their home countries for extended periods of time to visit the elderly relatives, family members left behind or to attend weddings of close relatives.

“....the other thing is as far as the Asian community is concerned, holiday means, going to Bangladesh for a long time. They do not take any short breaks. So, there are people who go for six weeks minimum and there are people going for two months, three months, six months, one year.” (Ian, Practitioner)

Practitioners expressed that people travelling back and forth between their home countries and where they lived in the UK often posed problems with people not being responsible to attend medical appointments and follow up of care. There also seemed to be an underlying tension as to whose responsibility it was to get the diabetes under control if there was a complete dependence on the practitioners when the professional trend in diabetes management is currently inclined towards self management.

“And that (travelling back and forth) of course is a real problem. They, they miss annual reviews, miss eye screening and it should, it shouldn't be our responsibility that they've missed it. It should be their responsibility. So, if

there's some way of getting people take a bit more responsibility for their health." (Miranda, Practitioner)

For the South Asian women in particular, going back home for extended periods of time was often enjoyable and they were often travelling back to visit elderly relatives, eat fresh food, enjoy the sunshine, attend weddings and socialise with their extended family members. As the husband of Haala, a woman from Pakistan explained, "*She likes to travel to Pakistan because of the sun, meeting up with relatives, she can go to the bazaar and eat everything fresh.*"

The practitioners expressed great concern over the lack of continuity of care, discontinuing of medications and the diabetes getting out of control while people travelled back and forth for long periods of time. There was also a concern with regard to how much medication could be sent along with the individual who could not be followed up for extended periods of time due to their travel in and out of the country.

"....when they go, they ask for quite a lot of medications but our law here says there is no defined rule how much medication you can give to somebody to take abroad. The law says what the doctor thinks as the reasonable quantity of medication is to go with them. I don't know what is reasonable." (Ian, Practitioner)

Medications were discontinued while they were in their home countries on certain occasions since they believed that the diabetes was not with them while they were out there.

"I know that when ladies go to Bangladesh or Pakistan or Saudi and they come back they'll say that they go over there and they are told they are not Diabetic and that its' not a problem." (Lyn, Practitioner)

"A lot of my clients say that when they go back home, they stop taking their medication. They feel completely fine." (Juhi, focus group)

“My, one of my clients came back from Bangladesh. When she went, she was like Diabetic and when she went she wasn’t taking her tablets on regular basis. So she has come in very serious illnesses. So she has to come back. So and she stayed here for about six months to get recovered and she went back and did took her Insulin and everything and she is getting prescriptions over there as well. But her husband was saying “Once you are there, you don’t have to take medications.” (Teja, Focus group)

“Patient Tourism”, as a practitioner described seems to be a major issue with the elderly women from Pakistan or Bangladesh which interferes with continuity of care and follow up.

“The other major problem I’ve talked about is the trotting backwards and forwards. You know, particularly the elderly ladies trot backwards and forwards between here and Bangladesh and Pakistan, you see. Just get them going on something (medication) and then they are off. And then they come back and we don’t know they are back. So, by the time they are back their control is going to have to start again. And that’s such a problem. And they don’t attend for eye screening or chiropody because they have left the country and then we’ve to start again referring them and it’s just eh eh really difficult. Really difficult to keep a track of them.” (Lyn, Practitioner)

“We have this major difficulty with South Asians in that they go back to Pakistan or they go back to Bangladesh and they don’t go back for a couple of weeks, they go back for eight or nine months. And so it is hard, I mean I have been here three years. It is hard almost to know who all we’ve got because by missing one appointment here and going back to Pakistan there, it’s hard to keep a handle on where they are.” (Miranda, Practitioner)

On the contrary, the South Asians who were interviewed as part of this study reported that they do exactly what they would do (continue their medications) while in the UK as far as medications were concerned.

“We go for a maximum of two months, that’s all but I take my insulin in the night in an insulated bag and then when I reach Bangladesh, I put it in the fridge so that when I go somewhere if I’m invited, I always take it. I know that they say if you keep it in the pen, if you keep it inside the thing, you can keep it for a month.” (Madhur)

“Well, I take all my tablets there, all the tablets I need I just take there like I take them here you know.” (Maasma)

There was one woman Rabia, whose interpreter reported that she had run out of insulin while in Bangladesh but still managed to continue the insulin as follows –
“She ran out of the insulin and couldn’t find it anywhere. So, it’s hard to find medicines in Bangladesh. You cannot get the same kind and she sent one of the relatives to get one from Sylhet. He went there three or four times to get and found only a couple of bottles of insulin and then they had to parcel some from England to Bangladesh.” (Interpreter of Rabia)

However, people expressed their difficulties with adhering to the dietary restrictions due to social and cultural reasons (demonstration of hospitality by offering food – sweets and fried snacks and turning it down would be considered impolite), traditional dietary practices (tea and coffee never being made without sugar) and the non availability of healthier options (whole meal bread, semi skimmed milk etc) while they were back in their home country but seemed to find ways around it since it was for a limited period of time.

“I go once a year for just a week or ten days. I don’t bother really. Probably, they haven’t got whole meal. They have chapattis. You know when you go there, you’ll be visiting people and they will give you rice as well and usually my sugar levels are more than here.” (Daanaa)

The perception by South Asians in general was that their diabetes control was better overall when they were back home due to good food and the hot weather that made them sweat considerably and sufficiently thirsty encouraging to drink plenty of water.

“I used to go back every year or so till I became so poorly. But I feel much better with my Diabetes when I go back there. I think it is the heat you know. That makes you thirsty all the time and makes you drink plenty of water. I think that is what makes my Diabetes better.” (Hadarah)

“It is better controlled in Bangladesh while he is there because of the hot atmosphere. He sweats and the diet is good as well in Bangladesh.” (Interpreter of Baqeer)

They generally seemed to feel well and remain active by visiting relatives, eating fresh food and being out in the open space.

“In Bangladesh, she is always active. Goes outside the house and there’s a lot of open space. They never sit in one place and they’ll always be moving around from one house to another, to the neighbours and that. They are always kept active.” (Interpreter of Rabia)

The possibility of having fresh food (vegetables, fruit and meat) everyday was highly valued and appreciated in the control of their diabetes when they were back home especially by the South Asians from Bangladesh as demonstrated in the following quotes.

“In Bangladesh, everything is fresh. You get fresh meat, you get fresh fish, fresh everything fresh vegetables but here it is not so fresh.” (Madhur)

“Here, you have meat all the time with dinner. There you have fresh vegetables and less meat and eat more fish and vegetables. It is very cold here

and you don't sweat here. But in Bangladesh, it is hot weather, it burns all the calories.” (Interpreter of Rabia)

It is interesting to note that the word “fresh” was emphasised by every participant / interpreter from Bangladesh in all the above quotes considering that they were different interpreters in each case and the interviews being done on different occasions.

Kiran from India differed in his opinion that his diabetic control was much better in the UK since he was careful about what he eats where as with food being a predominant feature of the Indian culture, he would have found it difficult to restrain himself from eating. He explains, “.....*I don't think so. Might be worse. You see, I love food. Who cares there? And the food, that was the main thing for us, you know. It would be everyday “I want this, I want...”*”

Heterogeneity within the culture

The practitioners were able to articulate the differences within the South Asian groups from their experience in caring for them. Literacy, ability to speak in English, the importance given to religion in peoples' lives and education seemed to be the distinct variations within the culture which in turn influenced the way diabetes and its risks were understood and managed. There were eleven women and nine men interviewed as part of the study ; seven out of nine men were able to speak in English fluently where as seven out of the eleven women were interviewed using interpreters. Eight of the women and five of the men interviewed were Muslims and religion was very significant in their lives as discussed in the earlier chapter.

It was also observed from the data that women from Pakistan or Bangladesh travelled back frequently to their home country and tend to spend extended periods of time there missing appointments and medications towards their diabetes management. The two quotes below highlight the relevance of education among South Asians in the way people understand and manage their diabetes.

“I think the more educated the person, the better they manage their Diabetes. And me own, my own personal finding is that we’ve some people from eh from India and they manage it much much better but they are professional people, they are doctors and you know people of a professional group. And the professional group still manage it better than the groups who aren’t professional. And I don’t know if that’s just a country thing you know.....”
(Lyn, Practitioner)

“I mean the Indian group are eh, eh again in my perception and it is limited. The Indian group in general are not very difficult. There are a few eccentrics within that group as we’d expect but in general they are educated. They are making decisions, informed decisions. They may not be exactly what I would want them to but they can speak English. They are supported by in general professionals, husbands or wives or it’s somebody in there is medical or pharmacist. They have relationships in the health care profession and their level of information seems to be good.” (Miranda, Practitioner)

There were differences in the importance given to religion among the South Asians as described in the following quotes.

“And where some patients will not fast, you know when you say to them it’s fine. I can say to them, “You should not fast on health grounds,” which I understand as a dispensation is allowed but then they have to give alms which is perhaps even less welcome than not eating and of course that hits them in the wallet instead of doing something which they feel like they would wish to do anyway. So, those are specific issues that I’ve had mostly with men from Pakistan. It’s just the way it works out. It’s just random, I suppose that hard liners I’ve seen have been from Pakistan rather than from Bangladesh.”
(Malcolm, Practitioner)

“(People from Pakistan) work hard and women again can speak English, mainly younger ones. Older women can’t... But they although they are a mixed bag, again it’s almost to do with how religiously adhered they are because that seems to be where the difficulties come... .. It’s not so much the religion but it’s the what that seems to take the.. the predominance over everything else. I mean everything, not just Diabetes but everything else. It is more important for them to ... to... to achieve whatever it is that they are supposed to be doing in the religion than our Diabetes.” (Miranda, Practitioner)

Lack of education and the introvert nature of the Bangladeshi community were perceived as the major difference which also posed challenges in providing services using shared goals and a participatory approach.

“They are not educated, the children are not educated. The children even are not as good at English. There is a real problem with perception. We have different perception. So, the same they are not shared goals... ..They seem to have turned into themselves a bit. This, I don’t know if that’s anybody else’s perception or interpretation at all but they seem to be more inward looking and trying to maintain their old structures rather than integrating into where they are. And because they don’t want to integrate, or are not integrating, we are not able to get the hooks to pull them in.” (Miranda, Practitioner)

Gender

The issues that came up with discussing gender influence on risk perception were based on the South Asians’ role perception, priorities, their response to diabetes, lifestyle issues such as exercises, and response to risks related to diabetes long term for both men and women.

Role perception

Women and men had different perceptions of their roles and responsibilities. Women perceived themselves to be ‘carers’ while men considered themselves to be ‘providers’.

Women tend to perceive their role within the family as a caring role – *“They think they are the carer of the whole family.” (Madhur)*

Men perceive their role primarily as the provider for the family – *“(Men) Work hard and so the management of their Diabetes is secondary to the role of being a provider.” (Miranda, Practitioner)*

Priorities

Women and men had different priorities within the South Asian culture and this impacted upon the way risks were perceived. Caring for the family and fulfilling the expectations of extended family members were priorities for women; men on the other hand, considered providing for the family, religion and health as their priorities. The family usually came first more than anything else especially for women. They perceived themselves to be healthy if they were able to carry out their daily responsibilities as carers as described below.

“Well maybe their health isn’t the first priority because they are kind of mothers and they always look after the children and look after their husbands and be a good wife. So, their health seems to come towards the end, you know.” (Lyn, Practitioner)

“.....especially for women, the family is a huge priority rather than their health. and it seems to be obviously, spouses, extended family and children, all of the time commitment within that extended family rather than their own health beliefs.” (Emma, Practitioner)

Men were also family oriented and since they were the providers for the family, they often focussed on fulfilling that role – “because the priority is to earn money or to support the family, I think.” (Miranda, Practitioner)

The other significant priority for Muslim men was to follow their religion and adhere to all the religious requirements – “...first of all I’m proud to be a Muslim. Yeah, my religion is very important to me.” (Anil)

“I’m a very religious person. So, the first and foremost thing that I’m proud of is my identity as a Muslim.” (Sa’ood)

Health was also mentioned as a priority by men during the interviews and they wanted good health to be able to work and earn to be able to provide for their families – *“If health is good, everything will be OK. People say money first, but I say health is first. If you have good health, you can do everything. If health is bad, what do you do? If health is alright, you can do the job, make some money...” (Abhaya)*

When discussions on exercises were made in relation to their lifestyle both women and men didn’t consider it to be important either due to their practical difficulties with accessing resources, time constraints, dislike, lack of appropriate venue, racism, cold weather, peripheral neuropathy (women) and working long hours outside their homes (men).

“It’s difficult here. If she goes to a gym then she could do some exercise but it’s hard to go out and go for a walk or anything. She’s always worried about the racism and things like that.” (Interpreter of Rabia)

“She is aware that exercises are good for her but she doesn’t like doing them. She also said that she doesn’t have the time to do them and the weather is too cold to go out.....She has been invited to go to the exercises groups that are run but said, “I can’t be bothered.” (Husband of Haala)

“They (men) do not do exercise. They are all very tense, stressed, lot of people who are obese. So, the main problem centred is around their way of life and diabetes is usually a burden they are not prepared to cope with.” (Ian, Practitioner)

Response in relation to a ‘crisis point’ varied significantly between women and men.

“The women come to a crisis point but just continue and thinking, “I can’t do anything about it, because you know, if you talk about exercise for instance... “Do you do any exercise?” “Well...” “Could you walk to school?” “Well, I could but my husband takes me in the car or, “Could you do this?” “Well,” and lot of it is not.....” (Lyn, Practitioner)

Women didn’t seem to take their diabetes seriously and they perceived themselves as the carers of the family often not recognising the fact that if they stayed healthier they could perform their care givers’ role even better.

“I think women in the community when they are ill, they don’t take it seriously. They think they are the carer of the whole family and they take care and ignore them (their health problems). So, that’s the thing happening within the community.” (Madhur)

“They (women) hear about it (risks). You say it to them that they go, “O! No.” Or they do. Like, they don’t realise how Diabetes can affect the whole of your body, everything, you know. I don’t think, that it clicks, somehow.” (Juhi, Focus Group)

“We had one lady attend this Bengali speaking group (for education on diabetes management) and she felt she couldn’t attend when her husband was in the home because she should be sort of around if he needed anything. And she couldn’t attend when he was out because of the children. So, it’s trying to

get an appropriate time for people (women) to come and attend the sessions is very difficult.” (Emma, Practitioner)

Men tend to take control of their diabetes management when they reach a ‘crisis point’ as explained in the following quote.

“I think with men it has to come to a crisis point. Men get to a point where everything is going wrong. Their blood pressure is up and their renal functions are not functioning well and their Diabetes HbA1C needs controlling and then when they reach a crisis point they think about it and think “Right, I must do something now and I must you know get this down” and they’ll go overboard and they’ll go and exercise and they’ll organise their diet differently.” (Lyn, Practitioner)

With men, when they come to actually having one of the risks, they seemed to respond better like in the case of Maahir from Pakistan who had had a heart attack-

“I started taking notice of the doctors, nurses and the dietician. Smoking in particular. I have tried to cut it right down. I used to smoke about twenty to twenty five a day and now I keep it at ten for two days. I find it difficult to give it up completely and need to have it after my meals.”

In relation to issues such as ‘power’ and ‘control’ men had a ‘higher status’ within the family and the freedom to express themselves when they felt unwell when compared to women as described in the following quote.

“When men have got an illness, not in our family, our family is different (Laughs) but in majority of the families, when men have got the illness, they show that they are ill. When a woman has got the illness, she just goes on doing all her responsibilities until she is bed ridden.” (Madhur)

It was also easier to bring about the changes required to manage their illness because of their status within their families.

“...We are talking about South Asian population then, quite often particularly if the males have a higher status within the family then changes will actually happen because of the male.” (Zoe, Practitioner)

Food was often prepared for the entire family and women didn't seem to have much choice to cook healthily even if they had diabetes as mentioned in the quote below.

“And another thing, one lady she said, “I cannot make, use oil because my husband, he doesn't like he says meal is not tasty, this and that. I have to make everything in ghee.” (Hita, Focus group)

On the contrary, food habits changed to healthier options if men (Maahir & Daanaa) had diabetes like mentioned earlier on in the chapter.

Women were also expected to look after the hospitality towards guests who arrived (without prior notice which is acceptable within the South Asian culture) sometimes at the expense of missing their hospital appointments.

“I think if family or somebody comes the woman will feel more important to stay and look after that person than to go to her exercise class or to go to a hospital appointment. It'll have to be really important appointment..... So then, the woman's health goes further down the list. I'm not sure if that's the same for men or not. But, so I do think there are reasons why women aren't, even if they wanted to and is able to look after their health as they might like to.” (Purva, Focus group)

The table below clearly represents that women were the ones who often missed hospital appointments. Despite the severity of their diabetes and the risk of developing

long term risks, women from Bangladesh in particular chose to miss hospital appointments frequently.

Table 3: Data obtained from the medical notes of older South Asians with Type 2 Diabetes

Participant	Frequency of appointment	Regularity with hospital appointments	HbA1C I (%)	HbA1C II (%)	HbA1C III (%)
Galina	Every 3 months	Regular	5-6	5-6	8-9
Hadarah	Every 3 months	Irregular	10-11	10-11	----
Chandana	Every 3 months	Irregular	10-11	8-9	9-10
Maasma	Every 6 months	Regular	6-7	6-7	6-7
Ila	Every 3 months	Irregular	>12	>12	10-11
Saabira	Every 6 months	Regular	8-9	6-7	7-8
Adya	Every 6 months	Regular	7-8	9-10	6-7
Padma	Annual	Regular	5-6	5-6	6-7
Rabia	Every 3 months	Irregular	>12	10-11	11-12
Madhur	Every 3 months	Regular	7-8	9-10	7-8
Haala	Every 3 months	Irregular	>12	10-11	10-11
Kiran	Every 3 months	Regular	6-7	6-7	6-7
Abhaya	Annual	Regular	6-7	6-7	6-7
Saadya	Annual	Regular	6-7	6-7	6-7
Daanaa	Every 6 months	Regular	6-7	6-7	6-7
Baqeer	Every 3 months	Regular	7-8	7-8	----
Sa'ood	Every 6 months	Regular	6-7	6-7	6-7

The recommended HbA1C level for someone with diabetes is below 7%. The above table clearly demonstrates that those participants who were irregular with their medical appointments had very poor glycaemic control. Interestingly, all of them were women (Hadarah, Chandana, Ila, Rabia & Haala). Most of these women said that they were regular with their appointments during the interviews. The medical notes had

documentation of their missed appointments. Of these women, except for Hadarah from India, all the other women visited their home countries for extended periods of time regularly and did report in their interviews that they enjoyed being in their home country on long holidays visiting relatives or attending social gatherings such as weddings. All these participants also attributed to external locus of control in managing the long term risks related to diabetes.

Haala in particular mentioned that she had gone on a planned holiday for 8 weeks to Pakistan and didn't want to return back to the UK despite feeling unwell within two weeks of reaching there for the following reason – *“No. It was too hot and actually my grand children wanted to get back after two weeks but I said No way we were doing that. Our return tickets were booked and it is too expensive to go all that way for two weeks. So, we stayed for all the eight weeks.”* This also resonates with the fact that people weighed up risks and made choices depending on what was important to them and the consequences of taking those risks.

In relation to communication, there were more limitations with women when compared to men primarily because of the language barrier. Most practitioners expressed that there was a significant limitation with communication with women because of the language (English) barrier.

“I think language has got to be the biggest barrier, I think. Because you know women, women particularly don't speak English and often come with a family member. Sometimes don't speak English very well either but that's all we've got and we have to try and work with that and that's got to be the biggest barrier.” (Lyn, Practitioner)

With men, because of their ability to speak the language, there wasn't any difficulty usually faced with communication – *“I feel when you're talking' to men , most of the men speak English and their command of the English language is very good. So, that barrier isn't there straight away. So you're actually doing a one to one.”* (Cheryl, Practitioner)

The other variation that was identified was ‘needle phobia’ which had implications on attending hospital appointments, monitoring blood glucose levels and taking insulin as prescribed; These were necessary towards effective management of diabetes and the prevention of long term risks. This was again very common with women and often resulted in not wanting their blood tested or having insulin prescribed even if their diabetes control was suboptimal. Women believed that their energy levels are sapped if blood was drawn. They had ‘needle phobia’ to an extent where they missed hospital appointments.

There was an instance where a woman was so terrified of having to take insulin despite her very poor diabetic control and her (Haala) response was “*When we go to the clinic, we pray that we will get a good doctor who will not force me to take insulin.*”

“She misses appointments at the hospital because, they take too much blood each time.” (Husband of Galina)

There were other instances where a woman expressed that she was ‘angry’ with the doctor when insulin was prescribed for the first time due to her fear of needles.

Gender differences have been reported in people with Diabetes. Health care decisions are often discussed within the immediate family in the South Asian communities because of the close knit family structure. Men play a major role with most health care decisions when compared to women. With diabetes, men were found to be more pro active in incorporating the lifestyle changes that were required and worked towards minimising the intrusiveness of the disease on their lives. On the contrary, women seemed to be consumed by the restrictions they perceived that diabetes had imposed on them. They also considered living with diabetes as stressful since it demanded constant vigilance (Koch, 2000; Koch et al., 1999).

Key Summary

Religion and spirituality were given the topmost priority in their lives especially among the South Asian Muslim men. This had predominance over everything else (Health, diabetes, family etc). This in turn also predisposed them to having a fatalistic attitude towards their diabetes (out of their control since it was predestined) and its related risks along with a sense of helplessness. Medications were discontinued while on ‘Hajj’. Diabetic control seemed better during their pilgrimage (Hajj) possibly due to the extensive physical activity (walking several miles a day). However, the diabetic control was attributed to the fulfilment of religious duties. Risks were weighed or ranked when faced with having to make choices between fulfilling religious requirements (Fasting during Ramadan while on anti diabetic medication) versus risking a hypoglycaemia or sub optimal diabetic control (missing medication due to fasting). Risk preference was to choose the former (fulfilling religious requirements) which was driven by personal priorities, strong religious beliefs that life belonged to God and the external locus of control.

The non Muslim South Asians valued health as a priority but diabetes wasn’t perceived to be an illness with serious long term risks.

Family is a significant priority among South Asians and people tend to live in joint families with multigenerational and extended family members. Family support was highly valued in caring for one’s diabetes. Decisions regarding diabetes management, especially in relation to food, seemed to be influenced by perceptions of agency (individual versus family), power or control that the individual had within the family, gender and social expectations.

Food had social significance and symbolized hospitality. When changes were required to be made especially in relation to diabetes management, it was either made by the whole family or not adhered to. Families that were extensively supportive and positive with the changes that were required to prevent long term risks for the individual with diabetes interestingly had health care professionals within the family.

South Asians tend to negotiate risks especially when faced with having to make choices with eating something (sweets) versus turning them down on a social occasion. They preferred to risk their diabetic control that was invisible and non imminent by complying rather than risk being socially offensive which was visible and imminent.

Perceptions on ageing varied and South Asians consider themselves ‘old’ in their fifties. Ageing was viewed in terms of accomplishment of their “duties” within marriage and responsibilities related to providing and caring for their family. Also, with Type 2 diabetes being usually diagnosed in later life, people didn’t find it very relevant to make drastic changes in their lifestyle. A fatalistic attitude towards health in relation to ageing was predominant accompanied by a sense of helplessness.

Leisure was almost never mentioned either by South Asian men or women. Holidays usually meant going back to their home countries for extended periods of time especially for women. This had serious implications in terms of continuity of care associated with discontinuing treatment resulting in poor management of diabetes which increased their vulnerability to long term risks. Poor diabetic control and feeling ‘ill’ while in Pakistan or Bangladesh was acknowledged and yet when faced with the option of returning back to the UK within two weeks of travel to Pakistan, the riskier option of staying there for eight weeks as planned initially was chosen since it was perceived to be too expensive to travel that far for only two weeks. Risks were ranked and decisions were made. This was also driven by a strong external locus of control and the perception that their diabetes control was better overall when they were back home due to fresh food and the hot weather.

Literacy, ability to speak in English, priorities around religion and the ability to integrate into the culture that the South Asians had moved into varied across the three South Asian (Bangladesh, India & Pakistan) communities. People from India were mostly literate, fluent in English, acknowledged health as against religion as their priority and were probably able to integrate better into the culture they had moved into

because of their ability to communicate. People from Pakistan and Bangladesh in particular had expressed language and literacy as some of the barriers that they faced in accessing services and information to manage their diabetes.

Gender differences cannot be identified in isolation with the gendered ideology alone. There is a significant place for gendered practice in risk perception. Women and men have different duties to perform at home and in their work places. Traditionally, men tend to do more paid work outside their home and women are involved in unpaid domestic work. There is also further segregation of activities within the broad categories of paid and unpaid work and different priorities in relation to access to time and space and the use of time and space for both women and men. This is particularly true with the South Asian communities even today despite the fact that role expectations are being redefined drastically all over the world. South Asian men work mostly outside their home while the South Asian women assume the role of care givers and home makers. They were expected to be in charge of all the domestic responsibilities, child rearing and entertaining guests. It is still customary that the men in the family are served their meals first and the women are expected to eat only after the men have their food which is symbolic of the woman's respect for the man in the house irrespective of how irregular the meal timings become due to the men's responsibilities outside their home. South Asian women also prefer to be accompanied by their husbands while going outdoors and often require permission to be able to go out on their own.

Overall, there was a sense of helplessness among women probably influenced by responsibilities with their care giving role, the dependent role on their husbands, social and cultural expectations and language barriers. Women had difficulties with accessing health care resources due to several constraints as discussed earlier. Men on the other hand by virtue of their status within the Asian culture had the authority to bring about the changes required at least when it came to a crisis. Accessing resources when required also was not an issue with men since they had the independence to make that choice unlike South Asian women in addition to the language (English) skills that they possessed.

Conclusion

It is clearly evident from the data that religion and spirituality, family dynamics, the significance of food within the South Asian culture, perceptions on ageing, meaning attributed to health, and the significance of travelling back frequently to their ancestral homes (holidays) were the predominant socio cultural and religious factors that influenced risk perception among older South Asians with Type 2 diabetes.

The key gender variations were in terms of role perception, priorities, communication, regularity with hospital appointments, response to crisis (in diabetes), management of diabetes and lifestyle related issues such as exercises. It is very clear from the data that women within the South Asian community are dependent on their families, subjected to different social expectations when compared to men and are primarily responsible for ‘looking after’ their families and children. They are also vulnerable because of their inability to speak the language (English) and are not able to make ‘choices’ that they would like to make because they do not enjoy the same status within the hierarchy as South Asian men do. Consequently, their response to risk is often resilience with a sense of helplessness. Most women seem content with their care giving role since they are brought up with that as being their life’s vocation from a very young age within the South Asian culture and tradition. Men, on the other hand assume the ‘provider’s role’ with male dominance within the hierarchy. There is a very distinct segregation of roles, responsibilities, power relation and gendered ideology within the South Asian culture. These have a significant bearing on the way risks were perceived.

Most of the religious and socio cultural factors operated from within the affective domain of the individual and influenced risk perception as described in this chapter.

CHAPTER: 7

RESULTS

RISK PREVENTION: PRACTITIONER VERSUS SOUTH ASIAN PERSPECTIVES

There is a paradigm shift from determining the probability of adverse events to assessing the scale and range of possible consequences that would result from being vulnerable to certain risks (World Health Organisation, 2002b). Science and medicine understand and define risk quite differently to that of lay people. Risk is viewed as an objective reality that can be measured, controlled and managed by the scientific community. It is widely believed that with the application of knowledge and having remedial actions and anticipatory measures to minimise the effects of risks if put in place, it would be possible to contain and harness risk. As far as the individual is concerned, risk is central to his or her experiences in life and it is socially constructed (Clarke, 2000).

The relationship between the evidence of medical science and social environments is not very clear cut. This often leads health and social care practitioners to discount the cultural and political dimensions of risk knowledge (Douglas, 1992). Traditional scientific practice also tends to professionalize risk. The emphasis is usually placed on safety and physical aspects of risk that tends to result in a scientific preoccupation with risk related consequences, as against risk perceptions. Health care practitioners tend to medicalize risk. It is therefore relevant and appropriate that specialities such as psychology and other social sciences respond to the need to determine risk perception (Althaus, 2005).

Health promotion is an integral component in chronic disease management and risk prevention. This has propagated interest in accessing lay views with health related issues and also in particularly understanding how meaning is attributed and practised

within the relevant socio cultural context (Milburn, 1996). Health promotion and health maintenance strategies are inclined towards self care in diabetes. The choices affecting health and diabetic control in an individual with diabetes are made by the individual since it involves life style issues and not just a medical consultation or taking medications as prescribed.

Data was collected from multiple sources to gain “rich” and in depth information on patient practitioner perspectives on diabetes related risks. Individual interviews were conducted with older South Asian men and women with Type 2 diabetes, practitioners which included three physicians, three Diabetes Specialist Nurses and a dietitian and focus group interviews with Ethnic Health Development Workers who were involved in providing services to this group of people in order to collect data.

This section describes in detail the varied perspectives of practitioners and South Asians in relation to priorities, risks related to diabetes, perceived barriers and locus of control influencing risk perception and the issues related to diabetes management. There were differences in the perspectives related to the cause and management of diabetes and perceptions on the severity of illness. These factors have been discussed along with other personal factors influencing risk perception in Chapter 5. The primary focus of this chapter in relation to the conceptual framework on risk perception is the influence of locus of control on risk perception among South Asians with diabetes. Perceived behavioural control (control beliefs) from the Theory of Planned Behaviour has its origin from perceived self efficacy of the Health Belief Model (Rosenstock, 1985). Perceived self efficacy refers to “.... people’s beliefs about their capabilities to exercise control over their own level of functioning and over events that affect their lives” (Bandura, 1991). However, perceived behavioural control focuses on the ability to perform a specified behaviour.

The practitioners ‘medicalized’ the risks related to diabetes and emphasized the role of self management in preventing long term risks. In line with the current national standards and trends in diabetes care, people with diabetes are expected to assume responsibility for managing their diabetes. Diabetes Self Management Education

(DSME) (Funnell et al., 2008) that aims to support informed decision making, self care behaviour, problem solving and active collaboration with the health care team in order to improve clinical outcomes certainly requires the locus of control to be internal. To the contrary, most of the South Asian participants interviewed, engaged with the risks involved with a strong external locus of control. Despite risk awareness (involving cognition), there was often incongruence between the cognition and behaviour involving the role of affect. People were aware of the risks involved, knowledgeable that the risks were not favourable and yet chose to engage with the risks reactively which was driven by their external locus of control and their socio cultural / religious beliefs as discussed in the previous chapter.

The practitioners identified several other barriers such as language, literacy and their own lack of understanding of the South Asian culture in addition to the strong external locus of control among the South Asians with diabetes.

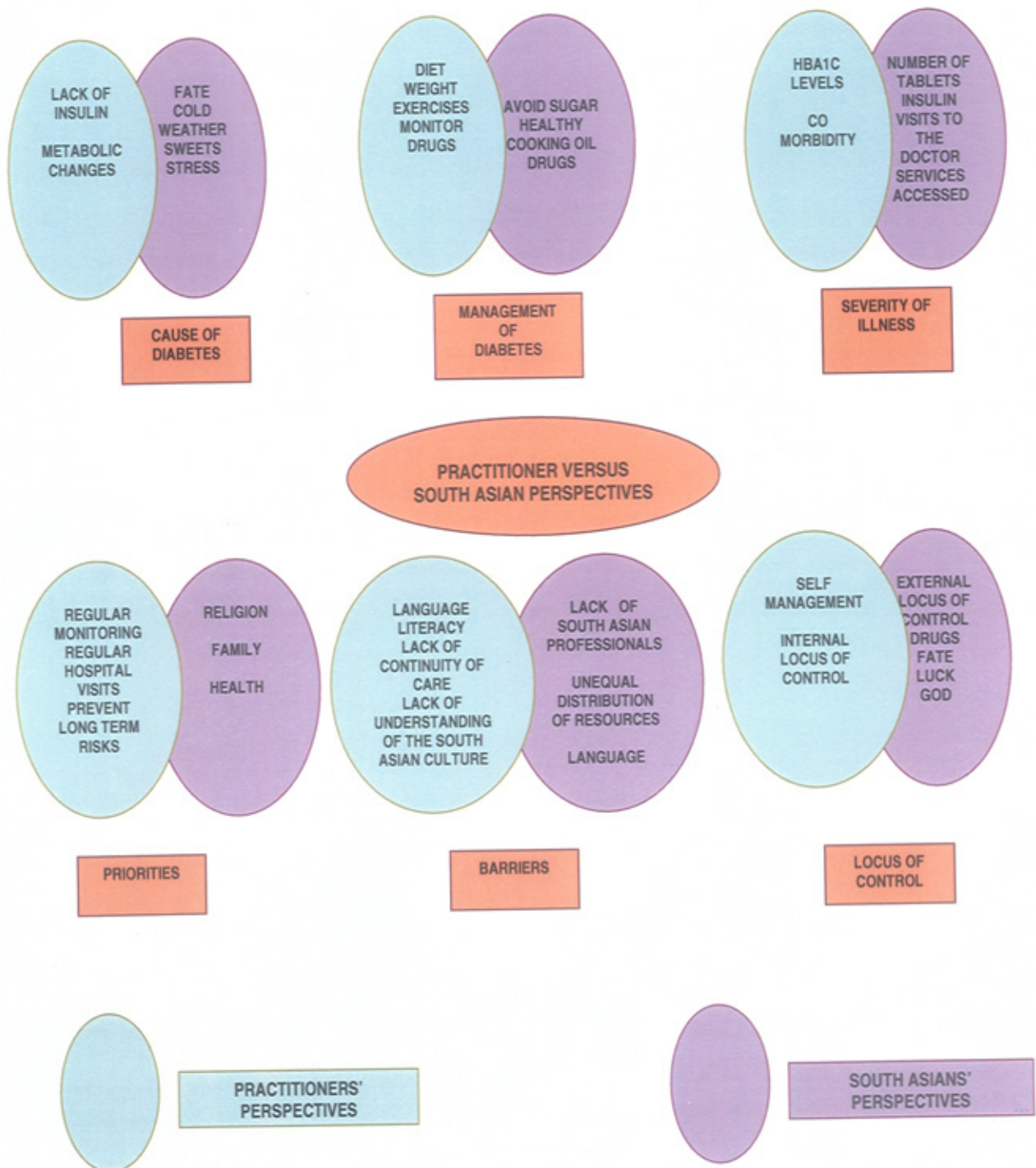


Fig. 14 – Risk Prevention: Practitioner versus South Asian perspectives

There were definite variations between the perspectives of practitioners and South Asians in relation to the cause and management of diabetes, perception about the severity of illness and priorities. The key variations are presented in the above figure. The following section describes the varied perspectives on perceived barriers, locus of control, risks related to diabetes and the issues around diabetes management between practitioners and South Asians with diabetes.

Barriers

The barriers that came in the way of diabetes management which in turn impacted risk prevention were communication, literacy, use of interpreters, lack of understanding of the South Asian culture, and the unequal distribution of services and resources that could be accessed.

Communication

Communication was a major issue especially in relation to the limitations with language skills and using interpreters particularly with South Asian women. Practitioners often expressed frustration with the limitation they had with language in understanding and being understood by South Asians with diabetes. This seemed to seriously interfere with the giving and receiving of relevant information related to diabetes management and the prevention of long term risks. Using interpreters didn't seem to be the solution either because the South Asians quite often preferred to bring along a family member who had some fluency in English for interpretation during a hospital appointment.

As one practitioner expressed, "I think language has got to be the biggest barrier, I think. Because you know women, women particularly don't speak English and often come with a family member. Sometimes don't speak English very well either but that's all we've got and we have to try and work with that and that's got to be the biggest barrier." (Lyn, Practitioner)

“.....but if you’ve got a lady whom you can’t communicate with it’s very difficult to get that over through somebody else and interpreters aren’t the answer because I don’t think they just don’t like interpreters. They prefer to have a family member.” (Lyn, Practitioner)

Even if interpreters were used for the hospital appointments, with the current emphasis in diabetes services being Primary care services with community orientation and Helpline services to promote wider access, the language and communication barrier made it particularly difficult to follow up and advise South Asians with diabetes as another practitioner shared in the following quote –

“Language is a barrier. Often, we can get interpreter sessions for the actual attendance at the Diabetes centre. Obviously, a specialist nurse role, is to maintain contact and adjust insulin doses or umm.. give advice on medication and if there isn’t an English speaking person in the home, then that’s very difficult to do. Umm... and trying to coordinate your phone calls with when the English speaking person is in the home, is really quite difficult.” (Emma, Practitioner)

The South Asian men and women also found language to be a significant barrier for communication with the service providers and preferred to choose GPs or physicians who spoke their language or to take a family member along to interpret if that wasn’t possible.

“She used to go to the GP quite a lot because, before she had a Bengali speaking doctor but now it’s all different doctors. Some speak English, some speak Hindi. So, she’s got to take somebody else with her. It’s difficult for her to go on her own.” (Rabia)

“His sons help him with interpreting the language and he doesn’t find any difficulty other than that.” (Interpreter of Baqeer)

Literacy

Issues related to literacy compounded the difficulties that were due to the language barrier and interfered with service provision for South Asians with Type 2 Diabetes. The communication barrier with language was at least partially addressed by using interpreters. With English being the official language, all written communication that is sent out from the Health Services are in English. This was a problem for those families without an individual with literacy skills in English. People often missed out hospital appointments as in the following quote –

“One major problem in the practice is that the patients don’t speak English and majority of the people who don’t speak English, don’t read or write their own language which makes a very difficult situation in educating the patient. Even when I refer to the hospital, when they get the appointment letter they do not respond to it either because they don’t understand it or they don’t keep a record of when they have to attend.” (Ian, Practitioner)

Literacy wasn’t an issue with just English but extended to even reading and writing in their own native language. Even with the possibility of providing information related to diabetes care translated in different languages, the literacy issue would not help address the language barrier. As one practitioner mentioned, *“Sometimes, you know, they don’t understand. So, what I do is, I write in English and I give it to the interpreter to go and translate it and bring it to me. When they come and sit here, I show them and then to my amazement they can’t read it.” (Ian, Practitioner)*

However, this seemed to be a major issue with the older South Asians and women in particular. The practitioners themselves felt that this was changing rapidly with the younger generation since most people were born and also went to school in the UK.

Using interpreters

This was a controversial issue since the practitioners generally preferred to use professional interpreters to address needs such as confidentiality, empowering the individual with diabetes to have their voice heard and understand issues related to family dynamics with food for instance if there was poor diabetic control which the individual may not be able to disclose in the presence of an accompanying family member. There were also instances of a young child accompanying the individual to interpret during a hospital appointment since that was the only English speaking member in the family which wasn't ideal for interpretation.

“I think the language is a key thing for, for the South Asian groups. Umm... and particularly it can be very difficult when family member comes along. Umm... who feels that they are sufficient for communication but medical words and terminology is quite difficult to translate even from for you know, trained interpreters. So, eh... it's often a little bit difficult. In one of the areas that I've worked in is pregnancy and sometimes for the impaired, impaired glucose tolerance during pregnancy, Umm... the husband perhaps has been... has decided that he didn't need an interpreter and we often feel it's very difficult for the wife. We aren't entirely happy or comfortable with that but it's the difficulty of communicating, giving her the power to have somebody more proficient in their language.” (Zoe, Practitioner)

“...if they don't speak English, we're going through a family member or I mean if it's the interpreting service, sometimes the consultation can be more fruitful. But if it's a family member I feel as though we lose a lot, crossin' over Umm... the consultation and information goin' third party.” (Cheryl, Practitioner)

Practitioners also expressed concern over using interpreters who didn't have the experience or training to work with people with Diabetes and hence didn't understand the seriousness or the details of the information that were to be passed on to the

individual with diabetes during a consultation. This seemed to dilute the quality of information that was given as in the quote below.

“So, I have an interpreter but still that’s also in a effective level, and I find that even interpreting doesn’t convey my, what I want to convey to the patient and the patients do not understand the need for controlling blood sugar and the complications.” (Ian, Practitioner)

The South Asians often preferred to have a family member along with them for a hospital appointment to assist them with the interpretation even if an interpreter was available.

South Asian women in particular needed to use interpreters due to their limited language skills in English but preferred to use their family members for this purpose as one practitioner explained, *“Oh, now they (women) are a real challenge because they don’t speak English. They, so we need interpreters. We try and avoid family interpreters but we sometimes have family as interpreters because they turn down the opportunity of having an interpreter.” (Miranda, Practitioner)*

South Asian women in general and from the Muslim community in particular tend not to interact at all or interact only very minimally with people (especially with men) outside their family or community due to their socio cultural barriers and restrictions. There is also a class consciousness and a gender divide that is traditional among them which is practised even in present times. These were some of the reasons apart from their family support for which they turn down the possibility of using interpreters. This was shared by one of the practitioners as follows – *“And we asked the health development worker to come to clinic with the patient. And in clinic, that health development worker sat separate to the husband and wife and she said they don’t (sit along with the patient) and she didn’t go into the consultation. So, that to me was quite a learnin’ experience, that. There is things within their culture that I don’t know nothing about and really, these are the barriers.” (Cheryl, Practitioner)*

Other practical issues such as the need to book an interpreter in advance and the non availability of the same interpreter for subsequent consultations posed difficulties for the South Asians as one woman from Bangladesh expressed,

*“.....they need to book the interpreter. And also if like the same interpreter is used, then interpreter becomes aware of the patient. It is also helpful.
(Madhur, from Bangladesh)*

She also went on to suggest that permanent interpreters need to be made available within the Diabetes centre to address this issue and facilitate the process of continuity of care and follow up.

There seems to be an underlying tension between the service providers (professionals) and the service users (South Asians with Type 2 Diabetes) with regard to using interpreters to address issues with language barriers. The service providers seem to prefer wanting to use trained interpreters and the service users prefer having a family member for the interpretation.

Locus of control

The locus of control was mostly external both from the practitioners' and South Asians' point of view. This was influenced by their understanding of the disease, perceptions on ageing, priorities in life, culture, gender, spiritual beliefs and values. The spiritual and supernatural elements were often intertwined with their lives. The strong religious beliefs held, led to a sense of resignation or acceptance of their diabetes. Family being high up in the order of their priorities in life, the women tend to dismiss their own needs for the 'good' of their family. Optimal self management of Type 2 diabetes involves several life style changes such as regular exercise, dietary restrictions and weight reduction that place constraints on time especially for women. It was perceived to be far easier to take the medications as prescribed and assume that the professionals or the medications were in charge of their diabetes.

Health was viewed to be very important but there was a *sense of helplessness* with what the individual could do to remain healthy as stated in the two quotes below. Visiting the doctors regularly and the professionals caring for them were perceived to be the ways in which they could stay healthy.

“Very important (health) but can’t do anything. Just go to the doctor and check up and I have this short breath as well.”

“... Everybody look after and nothing just for me. After God, doctor, nurse and like you friends, everybody. I believe that.” (Adya)

Taking medications prescribed was sought as the only way of coping with their diabetes as articulated below.

“He says that the doctors give him the medicines. That’s the only way he can stay safe apart from that there’s nothing much he can do.” (Interpreter of Maahir)

Adya from India was asked if she knew what the long term risks with diabetes was, the following quote was her response. It was perceived that it was the *responsibility of the professionals* rather than the person with diabetes.

“I don’t know. The doctor knows.”

There was an instance where the individual felt that he was able to take some responsibility towards his diabetes management but there were limitations such as *stress and worry* that would affect his diabetes but were beyond his control.

“I think we can. Everyone can prevent. It’s preventable, you know. And if you have the awareness, if you know what it is, what is the cause and if you change your eating habits, you can avoid it. There’s no doubt about it. There are other factors you know like worries, stress and pressure. I think, they are not in your

control. So, this factor if it is quite serious, I think you don't have any control over it but from your lifestyle, you have control. So, you have to certain extent, some control but not total control.” (Sa'ood)

Fate and luck were also attributed to be responsible as to which way their diabetes progressed or worsened and it was associated with resilience or acceptance since it was perceived that there was nothing else one could do in that situation.

“Then he said, “You have got high blood pressure.” I try not to worry all the time but I don't know how to drop that blood pressure. Sometimes, when you've got a family, family wise you worry sometimes. But I don't really worry all the time. I say, “Never mind. What's in luck? If it's good, it's good. If it's bad, it's bad. We can't help if there is any trouble.” (Abhaya)

There were instances of both men and women with a strong internal locus of control, taking responsibility for their diabetes and being convinced that there was something that they could do to manage it. In these instances, the common thread that ran across in most cases was that they were strongly motivated individuals and there was either a health professional within the family or that the individuals themselves were educated and were fluent with speaking in English.

“My uncle was a doctor. My father was a doctor in India and I had Hygiene and Physiology. So, I think I knew the general basics myself.” (Padma whose son and daughter in law were both General Practitioners and live very close to where she lives).

In the following example, Daanaa was convinced that there was something he could do about his diabetes, recognised the fact that he was over eating and decided to stop that and see if it worked. The role of self awareness (“*I was over eating*”) and the internal locus of control (“*I'll just control it on my diet*”) were the key factors in achieving his diabetic control.

“My doctor who is now retired, he was from India and when we go there they always test your sugar and at that time my sugar was quite high. And he said, “You are diabetic.” I said, “I am” and he gave me a little card. Since then, I go there twice a year and then I got shocked. When I was weighed, I was nearly twelve stones or may be over and I brought my weight down to ten stones. He was worried. I just told him, “I’ll just control it on my diet”. He asked, “Did you starve yourself?” I didn’t starve but I was just over eating and I stopped that and that’s it.” (Daanaa whose daughter was training to be a dentist)

In the case of Madhur, she was very motivated about getting her blood sugars down and was hence very determined to do everything that was possible in her capacity to get it under control. She also attributed the reasons for the inadequate diabetic control was due to the misguidance from the professionals.

“I try to keep my, you know, lower, my blood sugar level lower. That’s what I want to do. And as far as you know, because as I told you, initially every time I went to the hospital, they said “It’s OK.” But it wasn’t OK. It was higher. If I had known at that time, I would have taken precautions, perhaps taken some food, at that time whatever I needed to do, I would have done that.”

“I’ve got... last time when I went to see the doctor, they said they found a little bit of retinopathy. That is why I’m saying you know, over these so many years if I had known it was not controlled properly, I would have taken precautions. Perhaps, it could have been prevented.” (Madhur whose daughter was training to be a doctor)

Her response and motivation have apparently been guided by the medical advice of her daughter and the past experience with her cousin dying with renal failure. Having acquired one of the diabetes related side effects supposedly due to lack of information, she was highly motivated with a strong internal locus of control to prevent further risks.

The practitioners felt that the locus of control among most South Asians with Type 2 diabetes was predominantly external to themselves and that they were often dependent on the practitioners or the health care services for support even for reminders with hospital appointments.

“I’ve been off three weeks I realised that one of the ladies had a Diabetic centre appointment. So, I rang her to see if she went. She goes, “No, I didn’t go. Why didn’t you remind us? ” I think, Ah! I’ve been reminding her for the past four, five years and for once I was off sick and I couldn’t remind her. So, she didn’t go. So, you know, just to take it like responsibility, know how serious it is that you have to attend your Diabetic appointment, not just to wait for somebody to remind you all the time.” (Juhi, Focus group)

“Give them ten tablets, they are quite happy to take them. Because you just take a glass of water and drink them down. But you know it is hard to get through to them that Diabetes on its own can’t be managed by medication. You know, you have to think about your diet, and your lifestyle which is hard I think to change for women.” (Juhi, Focus group)

The participants in this study belonged to two groups: those with an internal locus of control and those with external locus of control. South Asians who believed that their diabetes was due to fate, bad luck, divine planning, familial predisposition etc had an external locus of control in perceiving and managing their risks related to diabetes. There were instances where people did take their diabetes and the long term risks very seriously especially when they had an internal locus of control and were educated or had a family member as a health care professional. This is resonant with the findings from a study which examined the relationship between lay theories of diabetes causation and peoples’ self care behaviour and reported three categories of participants – ‘self active’ (personally active in their treatment), ‘other active’ (someone else was taking responsibility for treatment) and ‘non active’ (no one was pursuing treatment). They also reported that those who attributed events / heredity to

be the cause for their diabetes were ‘other active’ or ‘non active’(Hunt et al., 1998). The external locus of control influenced decisions around diabetes management and risk prevention as described below.

Issues related to diabetes management and risk prevention

Attending hospital appointments

South Asians not attending hospital appointments regularly was a major issue with practitioners since this affected the continuity of care resulting in poor management of diabetes. It was perceived by the practitioners that people didn’t attend hospital appointments due to travelling back and forth to their home country for long periods of time as discussed in the previous chapter, the appointment not being sufficiently important or other priorities as described in the following quotes.

“They are very poor at keeping appointments, very poor, you know. Out of all the patients, all of our Diabetic patients it would be the Asian population that don’t keep them. They just don’t turn up or maybe because they feel it’s not important or because they often they don’t want to know, you know they don’t want to know what the results are going to be or I don’t know and it’s very difficult , you know.”(Lyn, Practitioner)

The reasons for people missing hospital appointments were also multi factorial as another practitioner clearly explains –

“...even follow ups, we, we’re going to have to prompt them but you know, “Tomorrow you’ve got a follow up appointment.” Whether that’s (not keeping appointments) because they’re comin’ to a hospital, or whether that’s because they don’t read or write or speak our language and that we should and they’re dependent on a family member to tell them and the family member who has forgot, and the,

it's not that the patient isn't complyin'. It could be something as simple as that." (Cheryl, Practitioner)

Lack of continuity for extended periods of time often resulted in having to start all over again to optimise care and diabetic control.

"....what we do sometimes find difficult is when people leaving, number of particularly older, more senior members of the family who actually eh... travel back and up to, up to three or six months and so often miss a lot of appointments." (Malcolm, Practitioner)

"They default clinic, we lose them for a year. They go to the GP because they have recurrent infections. The GP refers them in as a new patient again and we try and start again on the cycle." (Cheryl, Practitioner)

From the South Asians' perspectives the reasons for not attending hospital appointments were some practical issues such as lack of memory, not having a family member to accompany them since that was very important to them, blood being drawn at each appointment, long hours of waiting at the clinic and the anxiety which elevates the blood pressure while waiting to see the doctor.

"Sometimes they forget, sometimes they don't know, sometimes they haven't got anybody to accompany them." (Madhur)

"They take too much blood each time. I don't like that. My arm gets very sore. My blood pressure is OK when I go to the GP but every time I go to the clinic, it goes very high. I don't know why. Sometimes you have to wait in the clinic for a very long time and sitting in the clinic, I feel very tired." (Haala)

Haala, has also been reluctant to start herself on Insulin for several years despite extremely poor diabetic control. The need for starting insulin had been reinforced

during each appointment and that's probably also one of the reasons as to why she was not very keen on her hospital appointments. She was convinced that insulin was not good for her and the doctors were wrong as described in the following quote –

“I don't want the insulin because they are always telling me that insulin is good for me but insulin is no good. It makes the sugars go very high.” (Haala)

The data gathered from the South Asians revealed that there was awareness of the long term risks involved with diabetes for most people except a few occasions where women especially mentioned that they were not knowledgeable about them as in the following quotes.

“Don't know, I'm not educated.” (Galina)

“No. I don't know. I try not to eat too much sweets or fried things.” (Hadarah)

Engaging with risks was influenced by their locus of control which was mostly external and the resilience with which they viewed life in general as outlined in the quotes below.

“Her husband affirmed very strongly that everything was in God's hands and that there was nothing much they could do as human beings.” (Field notes of Haala)

“I have one Asian man who absolutely believes Allah will protect him and he won't get any illnesses and he won't take any treatment and he's kind of got glaucoma now. He's got kidney.....(dysfunction), you know he's really ill with his Diabetes but his right that he maintains that Allah will see him alright.” (Lyn, Practitioner)

One of the participants was also the primary carer of his severely disabled son and his response to being diagnosed to have hypertension in addition to diabetes was as follows:

“Then he (the GP) said, “You have got high blood pressure.” I try not to worry all the time but I don’t know how to drop that blood pressure. Sometimes, when you’ve got a family, family wise you worry sometimes. But I don’t really worry all the time. I say, “Never mind. What’s in luck? If it’s good, it’s good. If it’s bad, it’s bad. We can’t help if there is any trouble.”
(Abhaya)

Haala from Pakistan was quite knowledgeable about the risks involved but was very resilient about them, saying that there was nothing much one could do about preventing those risks irrespective of where they lived.

“I know that it can affect my eye sight. Doctor told last time that the right eye is bad. I know I can get heart attacks but I am not afraid of anything. You can’t do anything to stop them. You can only pray and God can help. Everything is in God’s hands. Nothing can be stopped. Even if I stayed in Pakistan, it would have been the same. Who knows? Only God knows.”

Long term risks related to diabetes were viewed as being due to lack of resistance or immunity and the body being unable to cope rather than the pathological changes that accompanied diabetes as described in the two quotes below:

“Well, prevented as long as you are, you have the resistance, you have reasonable health but if I have some severe attack of I mean, may be anything you know, flu, serious flu attack or may be a touch of stroke or anything you know. So, your system you know, if your resistance system goes weak, then complications automatically come.” (Sa’ood)

“Immunity, you know, it cuts that down. It makes you more weak, you know, to get more diseases and it takes more longer to get yourself cured, you know.”

(Maahir)

With Type 2 diabetes being mostly asymptomatic for long periods of time except for vague symptoms such as fatigue, it didn't seem to make people feel really unwell. As far as the risks were concerned, people didn't seem to quite believe that they would actually happen until they were affected by it themselves. There were expressions of disbelief about the possible risks during the individual interviews by both South Asian men and women. As the interpreter of Galina put it,

“After complications, now she realised but before that never took it seriously. She is very fond of Elaichi (cardamom) tea with sugar and she used to take that a lot, all the time and she never realised she would get this complication (Peripheral neuropathy) because sometime you don't believe when everybody is saying, “Don't do this. This will harm you.” She thought, “That's nothing.”

“They told me all the problems that could happen with my diabetes but I didn't take it seriously at that time. When you are young, you don't think about these things. I started taking notice of the doctors, nurses and the dietician (after the stroke and heart attack). Smoking in particular. I have tried to cut it right down. I used to smoke about twenty to twenty five a day and now I keep it at ten for two days. I find it difficult to give it up completely and need to have it after my meals.” (Maahir)

There was another woman from India (Hadarah) who perceived herself to be very fit prior to her diagnosis and was actually caring for her husband who had diabetes and was quite ill. She explains what her response to her diagnosis was initially and what caused a change in her response – *“Nothing. I didn't take it very seriously. My husband had it and I looked after him. To tell you the truth, I didn't even take my tablets sometimes because I wasn't feeling unwell, you know. I took it seriously only when my doctors told me that my kidneys had failed because of my Diabetes.”*

The above examples clearly explain that peoples' perceptions of risks related to diabetes and the management of those risks were influenced by whether those risks were visible and obvious in their own lives despite the fact they were informed about the possibilities of those risks by their health care professionals.

Key Summary

Language was a significant barrier for most South Asians and this limited their access to information and services for diabetes management. Use of interpreters during medical consultation with its limitations is an approach commonly used to overcome this barrier. Gender and ethnically matched health development workers who are bilingual (Link Workers) are used in Primary care services. There were conflicting views regarding the use of interpreters. Practitioners preferred using a professional interpreter rather than having to use a family member for interpretation during a medical consultation to address needs such as confidentiality, empowering the individual with diabetes to have their voice heard which is based on the Western model of medicine. South Asians with limited language (English) skills preferred having a family member alongside to accompany them for hospital visits and interpret for them. It was also perceived to be symbolic of their family support towards managing their diabetes. Given the above issues with using interpreters, the cost involved and the family dynamics within the Asian culture, it would probably facilitate a family centered approach for Diabetes care, prevention and life style changes if a family member is involved to assist with the interpretation during a consultation.

Literacy with both English and their native script was another major barrier among South Asians which compounded the difficulties with access and utilization of services for diabetes. This in turn led to people missing hospital appointments since all the official communication in the UK is in English and inability to understand written information related to diabetes care even if it was translated in different languages.

The locus of control was mostly external among South Asians and the response to risks varied from depathologising the illness to resilience. In instances, where the locus of control was internal (Daanaa, Madhur, Anil, Padma) people were educated, fluent bilingually and had a health professional as their family member. Their awareness of risks and engagement with risks related to diabetes were influenced by strong internal locus of control. They were motivated and proactive with risk prevention like in the case of Madhur who requested for anti hypertensive agents to be prescribed when her blood pressure went high (she also had a recent experience of her cousin dying with renal failure secondary to diabetes) and was able to associate that hypertension could be indicative of an impending risk (diabetic nephropathy) since her daughter who is training to be a doctor had explained this to her (Field notes, Madhur, Page 198). She was able to communicate all this clearly because of her education and fluency in English.

Daanaa whose daughter was training to be a dentist was also proactive with his risk prevention with determination to lose weight by cutting down his dietary intake since he believed he was eating more than what his body required.

The locus of control shifted from being external to internal after actually acquiring a diabetes related risk as in the case of Maahir who developed a stroke and Hadarah who developed renal failure as a result of their poorly controlled diabetes.

South Asian – Practitioner perspectives on risks related to diabetes were very different. Practitioners defined risks exclusively from clinical orientation and logic that was based on scientific facts pertaining to cognition and reasoning. In relation to risks, they discussed about hypertension, nephropathy, retinopathy and stroke. South Asians had the inability to link up diabetes and the long term risks. Symptoms such as diminished vision or sensation on feet of existing or impending risks (retinopathy/neuropathy) were associated with getting old rather than poorly controlled or long standing diabetes. These were again influenced by diabetes being an invisible disease and their limited understanding of the disease.

Conclusion

There is an interplay between lay and scientific knowledge of risks especially in chronic diseases where health promotion is an integral component in preventing or managing those risks. For people of South Asian origin, their perception of the risks associated with Type 2 diabetes is shaped by a range of different factors as discussed in this chapter. The practitioners' perception of risks related to diabetes is influenced by the technical-rational model of risk management that assumes a Western approach to health and access to health care.

The findings from this study make it apparent that with the locus of control is mostly external to themselves among the South Asians and this would become a challenge that needs to be addressed while planning and delivering services. The different perspectives on diabetes related risks and risk prevention between practitioners and South Asians with diabetes will facilitate the understanding of the possible tensions that exist and need addressing.

CHAPTER: 8

RESULTS

RISK PERCEPTION

(Risk Awareness & Risk Engagement)

Researchers have been trying to engage with Risk and Risk theories for at least four decades now and risk is yet paradoxical in nature. Risk theories are a ‘strange mix of seeming contradictions’ (Althaus, 2005). In health disciplines, risk is central to professional practice, assessment and clinical decision making (Heyman, 1998). Risk perception and risk management are much more complex than the logical complex decision making process (Heyman, 1999).

Individuals with a family history of any chronic disease are aware of their predisposition to the disease and hence develop a sense of vulnerability (Walter et al., 2004) that goes along with it. Practitioners find it challenging to understand the choices patients make despite risk information and consider it ‘irrational’ (Sultan et al., 2002).

Professionals within health care settings tend to focus and pay significant attention to the tangible physical safety aspects of risk as demonstrated by the practitioner perspectives on diabetes related risks in the previous chapter. In this light, risk perception is often viewed in the context of non adherence. Attempts have been made to understand non adherence using the Health Belief Model (HBM) (Janz et al., 1984) which proposes that adherence is related to perceptions around vulnerability to the disease and the perceived seriousness of its implications. This in turn leads onto appraisal of the potential benefits in terms of prevention and disease management. Decisions to adopt the required or recommended health behaviour are based on subjective judgment.

A common understanding of individual risk behaviour is that individuals take risks based on consequences in terms of losses or benefits as a result of taking that particular risk. The possible negative outcomes that occur as a consequence affect only the individual. The risks that an individual deliberately takes are perceived to be well thought out, more controlled and hence less threatening (Sjoberg, 2000) with a strong element of personal choice. Another interesting dimension of risk perception is that it could be differentiated as individual versus societal (Tyler et al., 1984). Interpersonal communication and information shared by family and friends influence risk perception and preventive behaviour.

Risk perception is not something that is easy to be researched because of its multidimensional, abstract and paradoxical nature. Evaluating risk perception on its own without considering risk engagement which results from risk perception may not be very meaningful and complete. This chapter attempts to highlight risk perception and risk engagement among older South Asians with Type 2 diabetes that would enhance the lay understanding of risks in chronic diseases such as diabetes among health professionals.

Personal and socio cultural factors influencing risk perception in this population and the practitioner – South Asian perspectives in relation to management of diabetes and the risks related to diabetes were discussed in the three previous chapters. Understanding of diabetes, perceived severity of diabetes, personal experience with diabetes related risks, immediacy of the risk and its visibility influenced risk perception which in turn resulted in risk awareness.

Risk Awareness

Risk awareness was present among South Asians with Type 2 diabetes as evidenced in the following quote.

‘He feels that if the diabetes gets worse, his heart will have to work harder. He says they are all parts of the same body. So, if something goes wrong with one, everything goes wrong.’ (Interpreter of Baqueer)

Risk awareness didn't necessarily result in proactively engaging with those risks or work toward risk prevention in the above instance. Baqueer had a very strong external locus of control and believed that the only way he could stay safe was to take the medicines that were prescribed but interestingly also chose to observe a fast during Ramadan and change the timing of his medications without seeking medical advice since he believed that doctors could only help but it was 'Allah' who gives life.

‘He says that the doctors give him the medicines. That's the only way he can stay safe apart from that there's nothing much he can do.’ (Interpreter of Baqueer)

‘He doesn't think so (able to prevent risks). He says it was due to bad luck. Nothing is in his hands. God gives illnesses.’ (Interpreter of Baqueer)

The cognitive information on risk awareness didn't result in risk engagement based on logic but was rather influenced by his religious beliefs.

Risk awareness led to proactively engaging with risks and working towards risk prevention when there was internal locus of control, literacy, self efficacy (belief in one's capabilities to perform the recommended health behaviour) (Bandura, 2001), bilingual language skills, personal experience with diabetes related risk and having a family member as health professional and motivation as in the case of Maadur and Daanaa.

Risk awareness was also influenced either through a personal experience with diabetes related risks or having witnessed someone among their family or friends being affected. Hadarah who had renal failure, retinopathy and neuropathy related to diabetes was aware of the risks as mentioned in the following page.

“I didn’t take it (diabetes) very seriously. My husband had it and I looked after him. To tell you the truth, I didn’t even take my tablets sometimes because I wasn’t feeling unwell, you know. I took it seriously only when my doctors told me that my kidneys had failed because of my Diabetes.” (Hadarah from India)

“My feet at present. They are killing me all the time and I can’t walk even for a short distance. My life is finished after I have had this Diabetes for nearly 11 to 13 years almost.” (Hadarah)

“Risks are there because if you take excess of sugars and if you don’t take care, risk comes and you have to get rid of your life also. Risks are more because I’ve seen; practically I have seen my friends. They lose parts of them with amputation or something.” (Baahir)

“My brother has no vision. He got a Diabetes and the brother who was in America, he had a by pass, you see, and we had a sister in India. She has a heart problem and she cannot walk. Then another sister, she is a diabetic and she is uncontrollable.” (Kiran)

Risk awareness did not necessarily lead to proactively engaging with those risks as in the case of Hadarah who confessed to allowing indulgences with sweets as explained in the following quote who also had a strong external locus of control.

“By God’s grace I’m doing OK and I don’t want to lose my kidneys again. I must look after it and I try to do my best. I don’t eat any fatty food. I still eat some sweets you know to tell you the truth.” (Hadarah)

She also confessed during her medical consultation that she had missed her antihypertensives that morning since the BP was low but the BP on examination was very high. She regulates her insulin on her own depending on her food intake and the amount of sweets she had taken (*Field notes, Hadarah*). She was very keen to

preserve her kidneys that were transplanted with great difficulty but didn't seem to engage with the necessary preventive measures.

Risk awareness was also influenced by the lack of visibility and the non imminent nature of risks proposed in relation to their diabetes as described in the following quotes.

“I don't think they take complications seriously because they, because they are not, they are not immediately there. Do you know, what I mean? They don't, they can't see what's happenin' to their kidney or how its goin' to affect long term. So, I don't think they take complications seriously.” (Juhi, Focus group)

“....Even high blood pressure. You can't see it. Can you?” (Purva, Focus group)

Something more obvious such as a gangrene of the toe seemed to draw immediate attention as being connected with diabetes rather than something like hypertension or renal disease which is less visible and less clearly attributed to diabetes - *“...if you had gangrene on your feet or something like that and then you sort of “Oh! That's got something to do with my Diabetes”. That might pick, you know.....” (Juhi, Focus group)*

Understanding of diabetes, perceptions on the severity of their diabetes and personal experiences with diabetes related risks influenced risk awareness in this population as described in Chapter 5. Risk awareness in turn influenced responses to risk that resulted in risk engagement.

Risk Engagement

South Asians with diabetes engaged with risks through risk response, ranking or prioritizing of risks, risk repair and creating safety nets around risks. Individuals

engaged with preventing or managing risks around their diabetes either proactively or reactively. South Asians who engaged positively with risks had a strong internal locus of control that was facilitated by their literacy, bilingual language skills, presence and support of a health care professional within their family, personal experience with a diabetes related risk and motivation as in the case of Madhur and Daanaa.

The following field notes that were made during one of Madhur's visits to the diabetic clinic very clearly depicts her motivation towards achieving good control in order to prevent long term risks related to her diabetes.

Madhur came to the clinic on the 08th of Feb. accompanied by her husband. She seemed very restless and apprehensive. The first thing she asked the consultant was if an ACE inhibitor (antihypertensive drug) could be added to her treatment since her daughter who was training to be a doctor had asked her to do that. She was extremely worried and anxious about the protein leak in her urine and was able to understand that it had something to do with her kidneys. Her cousin in Bangladesh had recently died because of a renal failure due to Diabetes. She was also aware that if her blood pressure wasn't well controlled, her kidneys could be affected and she was very anxious since her blood pressure was elevated on examination. The consultant tried to reassure her and said that the BP would be very high if she continued in that emotional state. The BP was re examined and since it continued to remain high, the drug was added to her prescription list. Prior to this experience, for several years she also believed that her HbA1c level at 8.5 was acceptable as told by her doctors and she was put on high doses of insulin until her daughter who is training to be a doctor had explained to her that the acceptable range was around 7. She had then insisted that other drugs were added to her insulin to get her HbA1C levels down. She has currently developed some eye changes (retinopathy) and believes that it was due to her not being told about her diabetes control sufficiently. (Field notes, Madhur)

Self control was expressed to be another key factor that influenced risk response and proactive risk engagement. Padma from India clearly explains how she was particularly fond of “Bounty” (a coconut toffee) which she gave up because of her self control in the quote below:

“I told her (dietitian), “I do eat sometimes, I like Bounty (coconut sweet).” She didn’t say anything else but, “If you want to die, you can eat Bounty.” Since that day, I haven’t eaten a Bounty... ..There are some sweets that I even don’t like. They can be lying about in front of me. I just don’t like them. And I’ve got control.”

Risk Response

The risk responses were largely influenced by the socio cultural and religious expectations and the external locus of control.

Religious beliefs played a significant role in this area. Life was believed to be preordained and predestined to the extent that an individual had no control over what happens or the ability to reverse situations that they currently were in. There was no fear of the long term risks involved with diabetes since the course of life events (death) would follow as predestined, even if one took the necessary precautions to avoid those risks as described in the following quote:

“Being Muslim you know, we believe that the time of your death has been recorded before you come into this world in the womb of your mother you know, after the thirteenth day of conception. Nobody can change it you know. But nevertheless, it doesn’t, the faith doesn’t say, ‘You indulge in stupid things and you kill yourself’. You take all the precautions you know, whatever are available and then leave it to God you know. So, I think nobody can do anything about what time has been fixed. Nobody can bring it forwards and nobody can postpone it...” (Sa’ood)

Apart from adherence to their religious requirements, personal faith and hope had a strong influence in the way South Asians responded to long term risks related to their diabetes. There was a strong belief that their God (“Allah”) will see them through their illness even if they didn’t take their treatment or follow any medical advice that was required as evidenced in the quote below:

“I have one Asian man who absolutely believes Allah will protect him and he won’t get any illnesses and he won’t take any treatment and he’s kind of got glaucoma now. He’s got kidney, you know he’s really ill with his Diabetes but his right that he maintains that Allah will see him alright.....” (Lyn, Practitioner)

There was often resilience in the way people responded to risks around their diabetes. They believed that life had its course as predestined which couldn’t be interrupted.

“I know that it can affect my eye sight. Doctor told last time that the right eye is bad. I know I can get heart attacks but I am not afraid of anything. You can’t do anything to stop them. You can only pray and God can help. Everything is in God’s hands. Nothing can be stopped. Even if I stayed in Pakistan, it would have been the same. Who knows? Only God knows.” (Haala)

A resilient response involved taking things in one’s stride and carrying on as long as it wasn’t immediate or life threatening.

“Leg pain, my feet some little bit, starting here (Shows her feet) but problems yes, loads of problem. Eye problem. Every three months laser treatment. I’ve got loads of appointment. Going to the clinic, going to the diabetic clinic, feet clinic, sometimes doctor (GP), sometimes dentist, Oh God. Loads, but may be heart is strong. So, this is not a bother.” (Saabira)

Disbelief about the possibility of being faced with long term risks was yet another risk response that played a significant role. This was predominantly because people with Type 2 diabetes generally didn't feel unwell unless their blood glucose levels were extremely out of control or there were manifestations of complications. People didn't take the risks seriously until something actually happened as predicted. Personal experience with the proposed risks influenced the way risks were taken or avoided as explained by Maahir from Pakistan. He was a heavy smoker and didn't take things seriously until he had a heart attack – *“I started taking notice of the doctors, nurses and the dietician. Smoking in particular. I have tried to cut it right down. I used to smoke about twenty to twenty five a day and now I keep it at ten for two days. I find it difficult to give it up completely and need to have it after my meals.”*

Responses to risks around diabetes included ‘normalising’ and depathologising the disease as evidenced in the following quotes.

“I'm not looking at it as an illness. If you think, too much about the illness, then I become hell, you see. You cannot survive you see. You have to live with peace of mind as you have no illness or nothing like that. I try to have normal life”.

“It's one more disease I've added. Nothing else. But it didn't give me any trouble, Diabetes” (Baahir).

The risk response was denial in the case of Sa'ood where he did not believe that he had diabetes but was addicted to sweets and hence considered it essential to take the prescribed medicines as a license towards eating sweets as described below:

“Even now, I feel sometimes you know, I'm not worried. The perception you know, I think is it's very well controlled actually and I'm on tablets and I have a sweet tooth you know, I eat everything. There's no restriction. I eat sweets etc. Those tablets keep it very well controlled between 4 and 6 which is not

bad. So, sometimes I feel personally that if I stop taking tablets and stop eating sweets it will be alright'' (Sa'ood).

His response towards an existing cardiovascular risk that was due to his diabetes was also denial. He went to the extent of discontinuing all his medicines and medical tests that were deemed necessary for follow up on the risk.

“This is only psychological, you know, there’s nothing……. I took all the medicines and threw it out and never went for any more further tests you know.”

A fatalistic attitude regarding ageing influenced responses to diabetes related risks as described in the quote below:

“So, overall, people put a lot of things down to fate anyway especially when it comes to age, how long you’re going to live. And if you’ve lived a fairly reasonable life, you know you don’t bother, you don’t take that much of a consideration (to make the necessary life style changes and prevent risks) really.” (Anil)

Interestingly, in all the above cases, the locus of control was external. With a strong external locus of control, the response to risk was one of powerlessness because someone else was in charge of their diabetes and the related risk prevention.

There was a sense of powerlessness associated with uncertainty about the future in preventing the long term risks involved. A woman went to the extent of saying that if qualified professionals are not able to manage her diabetes, she did not see the significance of her role in managing it as in the following quote.

“For the future, I can’t really tell because I really try hard and there’s only so much that I can do. Even the hospital can’t do much. They can’t get the sugar level down then how much could I do? I’m always trying and it all depends on

my luck and in God's hands whether it will be controlled or not. I don't know what will be the future.” (Interpreter of Rabia, Bangladesh)

Ranking of Risks

There were several situations described by the participants which required a decision to be made based on ranking different risks. This often happened in relation to eating practices, where the risk of causing a social offence had to be considered alongside the risk of less than ideal diabetes management as expressed below.

“When she goes to somebody's house you know, she cannot say that ‘I'm hungry. I need to eat’, because she is on Insulin and she has to see to the time of her meals. Same thing with the parties, she has to avoid the parties because of this.” (Interpreter of Saabira)

The other common area where people ranked risks was in relation to their religious observances or requirements. Fasting during Ramadan, going on ‘Hajj’ and attending prayers regularly were given a very high priority, especially among men. There were instances of people fasting without consulting their health professionals which involved taking insulin and adjusting their meal timings accordingly as their religion requires them to do so as explained by Baqueer in the following quote.

“No, because they (doctors) will say, “Don't fast and have the medicines. Doctors can't give anybody life. They just help you but it is Allah who gives you life.”

Diabetes was viewed as a trial from God. These trials were not only believed to be from God but also as a source of reward in their “life after death”. Their belief that their life on earth was temporal and there was an eternal reward when they were affected by diseases empowered them with the courage to continue with the disease. The belief also included that the reward that awaited them was proportionate to the number of trials that one had to face. Thus, when risks with non adherence to religious

requirements versus risks with non adherence to diabetes management were ranked, individuals chose to adhere with their religious requirements that were driven by their strong religious beliefs and convictions. Sa'ood describes this very clearly in the following quote.

“ , we personally believe that this is a short period given to us for a test and whatever we do, good or bad, you know will be rewarded hereafter and that is eternal you know, never ending. So, obviously, when you see that there is a reward to you for these diseases, illness, sickness etc then it gives you courage..... ”

There were other instances where women especially chose not to fast on health grounds as there were other forms of dispensation that could be made instead, as described below.

‘I pray and do other things you know, but fasting, I don't do fasting but I know that because of my illness and our religion allows it if you are ill, you don't have to fast but lots of people I know in the community, they have diabetes but they are still fasting.’ (Madhur)

Risks were ranked when choices had to be made between giving up personal preferences (alcohol, travel etc) that individuals enjoyed versus maintaining optimal diabetic control towards prevention of long term risks. Choices to continue with their personal preferences were favoured especially when the benefits were visible, immediate and tangible and the locus of control was external.

Abhaya who had previously had a stroke due to his diabetes, ranked the risks between continuing alcohol (his personal enjoyment that was immediate, visible and tangible) as against giving up alcohol to improve his diabetic control (non imminent, invisible and non tangible) and chose to continue having alcohol as he explains in the following quote.

“I tell them (doctors) the truth all the time. But I still drink what I like. I told the doctor even, “Doctor, I’m still drinking.” Lot of people tell me to stop drinking. If I stop drinking, I’ll get better. It’ll be OK. It will be a little bit better but nought fully. So I say, “What’s the difference? I’m drinking what I like...””

Traveling back to their country of origin for extended periods of time was a priority especially for women. The following field notes from interviewing Haala from Bangladesh clearly illustrates that staying back in Bangladesh despite feeling ill with very high blood glucose levels outweighed the need to return back to the UK within two weeks considering the expenses involved. She perceived that it wasn’t worth spending such a lot of money to go all that distance for a short time. The fact that her husband wasn’t with her and that she was responsible for her two young grandchildren who had accompanied her didn’t deter her decision.

She usually travels with her husband and for the first time last year she went with two of her grand daughters (10 and 12 years old). Her diabetes is very well controlled when she is in Pakistan usually but this time everything went wrong. She also had to stay at her cousin’s place and hence didn’t have the flexibility with her diet. Her sugars were very high all the time. So, I asked her if she thought of coming away earlier than planned she said, “No. It was too hot and actually my grand children wanted to get back after two weeks but I said No way we were doing that. Our return tickets were booked and it is too expensive to go all that way for two weeks. So, we stayed for all the eight weeks.” (Field notes from interview with Haala)

However, individuals were willing to give up personal preferences when the risk involved was compromising on their family’s preferences. Ranking of risks involved choosing between one’s personal health and the family’s preferences. The husband’s likes and dislikes were considered far more important than healthier cooking especially when it came to South Asian women with diabetes where the cooking was mostly done by them for the entire family, as given in the following quote.

“One lady she said, “I cannot make, use oil because my husband, he doesn’t like ummm..... he says meal is not tasty, this and that. I have to make everything in ghee.” (Hita, Focus group)

There was another instance where a sixty nine year old woman from India shared how her husband had given her permission for her to sleep in the same room with him because of her recent hypoglycaemic attacks at night. Within the Asian culture, it is common practice that married couples do not sleep together past their child bearing age. This is probably because of the inhibitions that exist within the culture with expressions of sexuality and affection. People mostly live in joint families and hence it is considered socially unacceptable for children to see their parents sleeping together in the same room because it is perceived that sleeping together is solely for reproductive purposes. This woman had an unmarried daughter living with them in her house. It was interesting to note what she said in the following quote:

“She sleeps separately from her husband. People think that sometimes after age you know, the children are grown up now. Then she sleeps separately with the children as he was sleeping in his room but after her Diabetes, she has had low sugars and her husband said, “Don’t sleep separately. Sleep in my room.” (Interpreter of Saabira)

Both the above quotes also raise another important issue about “power” relations and “individual choices” that women had in ranking of the risks involved. It is obvious that the husband had more “power” in both situations and strongly influenced the womens’ choices in ranking risks.

As for social expectations especially with women, hospital appointments were considered secondary and were missed if they had to entertain a guest who was visiting unexpectedly. Hospitality is expected to be practiced by the women as part of their caring role within South Asian families and a guest arriving unexpectedly was acceptable within the culture.

“I think if families come, you’ve , I think if family or somebody comes the woman will feel more important to stay and look after that person than to go to her exercise class or to go to a hospital appointment. It’ll have to be really important appointment.” (Purva, Focus group)

People were more confident of taking certain risks especially if they had medical expertise within their family. Madhur from Bangladesh was about to take a family holiday that had been planned for a very long time when she was advised to start insulin for her poor diabetic control. The choices before her were to cancel the planned family holiday and start the insulin with medical supervision or to start the insulin anyway and continue with the holiday plans abroad. She shared that it was her daughter (who was training to be a doctor then) who was also traveling with her who motivated her to take the risk and travel.

“....the doctor said, I have to take the insulin. I was concerned but then they were very... the younger one was eighteen years old at that time and the other one was nineteen. Just she started her medicine, then she was in the first year because and also because there is a need to adjust when you start but I didn’t have that problem because you know....I never had any problem to take the insulin, plus we had to eat in the restaurants when we are on holiday but I managed well. I was worried. In fact, one of my friends was telling me that “It would be risky for you to start the insulin just before you go on holiday, in case it doesn’t start adjust the dose then you’ll have to lower or higher the dose.” But we took the risk and we went.”

Risk Repair

There were also instances where people took actions to compensate for exposure to risks that may otherwise lead them to harm. Intake of sweets was a frequent risk to which people exposed themselves and repaired the possible damage that was likely to result from it (poorly controlled diabetes and long term risks) by either cutting down

the intake temporarily or taking extra doses of insulin / medication. People also modified what they ate as guided by their home glucose monitoring. The following quotes clearly demonstrate risk repair as a way of engaging with risks around diabetes. This also explains that their understanding of diabetes was limited in that they viewed risks as something transient that could be combated with temporary solutions (suspending intake of sweets until the glucometer readings were normal) as against practicing consistent lifestyle changes if one had to proactive engage towards preventing long term risks.

“She checks her blood sugars at home twice or thrice a week. When the readings are high (above 7), she stops eating greasy food and sweets for a few days till the readings come down. Once they are OK, she eats everything without any restriction.” (Husband of Haala)

Hadarah regulated her insulin dosage without medical advice depending on her food intake and the amount of sweets she had taken (*Field notes, Hadarah*).

“I have a sweet tooth. I can’t resist. I take sweets. So, I’ve started taking the tablets... .. Actually, if it (blood glucose levels) does go very high, I do stop (sweets) for a while. When I came back (from Hajj), it was a little high. So, I increased the tablet by one. So, it was controlled.” (Sa’ood)

Safety nets as a way of engaging with risk

There were selected instances where people with external locus of control were aware of the risks involved and created safety nets in place to proactively engage with risks at hand as described in the following situations.

Difficulties were expressed with having to take insulin while traveling back home and the international time differences while on the flight during travel. This was overcome by creating a safety net as follows:

“During the journey, having the insulin is very difficult. I take the clock you know. Time different over there. Five hour. For one week I keep here time, I change the time.” (Saabira)

There were occasions where women in particular created safety nets and worked around their diabetes when it came to fasting during Ramadan because of the risks involved as follows:

“She has got used to it over the years trying to adjust her lifestyle around Ramadan. Sometimes, she has to break her fast. If she realises she is getting a hypo (drop in blood sugars), she breaks it. The days she feels fine, she carries on with it.” (Interpreter of Ila)

Where people couldn't exercise self control especially when it involved restrictions with something they really liked, the safety net they used was to avoid being in that situation as illustrated in the quote below by Saabira from India.

“My lad asks you know, I used to make gulab jamoon (an Indian sweet) a lot. He says, “I want your hand made gulab jamoon.” I say, “I'm not make any more, no.” You know, I can't stop, (eating the sweet) you know. I have tried and no good. That's why not make sweet things, no.”

Key Summary

It is evident from the data that individuals with risk awareness chose to engage with risks either proactively or reactively. Factors such as perceptions on ageing, spiritual beliefs, the immediacy of the risk, resilience, socio cultural priorities, their ability to create safety nets and personal experience with facing the risk itself were central to their risk awareness and risk engaging behaviour.

Risk awareness was influenced by their understanding of diabetes, perceived severity of diabetes, personal experience with risk, the immediacy and visibility of risks related

to diabetes. Risk awareness resulted in proactive risk engagement only when the locus of control was internal which was facilitated by a combination of variables such as literacy, bilingual language skills, motivation, personal experience with risk as a consequence of their diabetes and the presence of a health care professional within their immediate family.

Despite risk awareness, engagement with risks was reactive when the locus of control was external and influenced by socio cultural and religious beliefs. Individuals engaged with risks through risk response, ranking of risks, risk repair and creating safety nets around risks. Risk responses ranged from denial of having diabetes to depathologising the disease. With an external locus of control, there was an attitude of resilience and powerlessness in responding and engaging with risks.

When posed with having to make choices between visible versus invisible risks, imminent versus non imminent risks, personal (health related) versus social or spiritual risks and personal preferences versus family preferences, it was invariably found that individuals with an internal locus of control made choices towards proactively engaging with risks and work towards ideal diabetes management. Those with an external locus of control were inclined towards making choices that were guided by their religious and socio cultural priorities such as hospitality and family preferences or fulfilling religious requirements. South Asians with diabetes in general, preferred to rank risks that were visible, imminent and tangible higher than those that were invisible, non imminent and intangible. Risk engagement also resulted in risk repair and creating safety nets around risks as described in the above section.

Conclusion

Risk awareness resulted in either proactive or reactive risk engagement. Proactive risk engagement was unique to those with a strong internal locus of control that was influenced by specific variables. Reactive risk engagement was predominantly influenced by socio cultural / religious beliefs and external locus of control that operated in the affective domain among older South Asians with Type 2 diabetes. Risk

responses varied from resilience to disbelief, normalising and depathologising one's diabetes. Risks were ranked on the basis on immediacy and visibility primarily. Attempts were made to repair risk as required and people engaged with risks by creating safety nets as described in the chapter.

CHAPTER: 9

RESULTS

THE WAY FORWARD

Traditional models of health care in general and diabetes in particular relied heavily upon individual compliance with practitioners' advice. Self care behaviour has been identified as the crucial component of diabetes management with integrated life style practices over the last two decades (World Health Organization et al., 1990) . The concept of patient empowerment advocates concordance as against compliance (Henshaw, 2006). Concordance reinforces mutual goal setting with practitioners facilitating patients with diabetes to make informed choices about diabetes management. The relevance of an empowerment model of diabetes care for older South Asians with Type 2 diabetes as against the traditional hierarchical model needs to be carefully scrutinised to ensure optimal utilisation and achievement of its primary goal which is long term risk prevention.

PRACTICE & SERVICE PROVISION

With regard to practice and service provision both practitioners and the South Asians had much to offer by way of suggestions for the future. With Type 2 diabetes being commonly seen among South Asians and the incidence escalating, **a family oriented approach** was preferred towards preventing the disease.

“They prefer to have a family member. But in some ways that is quite good because that is going to bring their son and daughters. You can actually, I find that I can educate the son and the daughter as well as educating the parent for if their time ever comes because as you know their risk is very high. A because of their genetic make up and B because they’ve got a family member that is diabetic. So, I think it’s quite good if they bring a son or a daughter in, then I could educate them.” (Lyn, Practitioner)

“I definitely agree with what has been in the discussion. But also I would add probably, you know GPs sit down with the whole family you know, also involving children and their children and stuff like that.” (Samir, Focus group)

With the dynamics of managing Type 2 diabetes being family oriented and the lifestyle changes required, it was expressed that it would not suffice to just deal with it on a one to one basis as expressed in the following quote:

“Like they’ve got the list of the patients. They are the one they know, who has got the diabetes. They can form a group and they can run various educational sessions with the people who have got the diabetes or even like not with the patient, with the carers because sometimes if it is men, he is not the one who does the cooking, organizing the food. In fact, from the Bangladeshi community, it is the woman nowadays, who does the shopping, cooking everything.” (Madhur, Bangladesh).

In terms of service provision it was felt that services needed to be more **uniformly available with wider access and increased cultural sensitivity**. Facilities such as an annual review for early detection of complications weren’t available in all the GP surgeries at present. Some patients were seen to by the GP while others were referred to the Regional centre and this also led to misconceptions about the severity of one’s diabetes. There was also a lack of standardisation in the way these services were run especially in terms of follow up. This was articulated clearly in the two quotes below.

“One of the other things is hopefully, within ten years access to services will be the same across the board because it varies so much from one practice to another. One doctor is quite willing to refer you to the Diabetes Centre and the other one says, “No. come to my surgery.” And for somebody who has been given that message, “O! He is going to the Diabetes Centre. So, he must be more serious than I am because I am just going to see my doctor.” (Dhiren, Focus group)

“I think I agree with Dhiren and like primary health care teams and the Diabetes centre, there should be a much more standardised thing. In some practices you go and get consistent care, you know, if you have Diabetes you get an annual review, you get a follow up with this and this you know. In other places, people don’t even know, you know, they don’t know when they’re supposed to go, if they’re supposed to go, what they’re supposed to get, so that is structured care.” (Purva, Focus group)

The need for **ethnic monitoring** by health professionals was also emphasised by Purva in the focus group if services needed to be more relevant to the South Asians with diabetes – *“And then, I would like all health professionals to be doing ethnic monitoring so that we can measure. So often we can’t measure things because people don’t do it. Everybody should have more training, so that they are more aware of like racial equality issues and deliver better services and (pause) like the empowering people is about, about workin’ with people but making sure all the stuff, that you know, you sort of plan, so we’re doing some awareness raising to be and that’s standard. But measuring it, we’re not measuring. We’re doing things and hoping it’s good for people. But we haven’t got sensitive measures.” (Purva, Focus Group)*

The model of involving **ethnic health development workers** in GP surgeries as link workers to provide services and education featured from the interviews with practitioners. The commonality of their background, language and a shared understanding of socio cultural and religious values, family dynamics and lifestyle issues were proposed to be the strengths of involving the ethnic health development workers in the service delivery and health promotion for South Asians with Type 2 diabetes as explained by a practitioner in the quote below:

“I have to say that the support workers have been a major step forward because ten years ago, this was a difficult to reach group and it was, you had no idea how your advice was getting home. The care was haphazard and I think at least in the knowledge, they have a foundation

of health beliefs which is common between you and them through those support workers. I think that's been a major thing and I think that's a very useful model and it's a good model for any chronic disease and health promotion. To have that given by specialist trained workers here in that sub group is excellent. I support that very strongly.” (Malcolm, Practitioner)

“If they had one sort of key worker who attended clinic and Umm.. then sort of followed up that information, because we all know that we need information again and again and again. And unfortunately, because we haven't got the supportive literature and things, they often get this information as a pure one off. And then nothing to support it further. So, may be there's a role Umm... whether that's a health development service or whatever to try and follow that information up and provide support.” (Emma, Practitioner)

Coordination of the available resources to use them more efficiently and make the services more streamlined was another suggestion in relation to service provision. Practitioners expressed from their past experience that trying to create new services each time was reinventing the wheel rather than achieving its purposes - *“And coordination as well, I think there needs to be much better coordination of life style things because there's heart disease, Diabetes, cancer, stroke. We're all workin' on life style issues. Community organisations are doin' it, health are, local authority, voluntary groups but in my mind those issues are not well enough coordinated. And that means then, we're all beaverin' away tryin' to get some people to come to our group of things whatever it is. And then they might be asked by another two or three groups.” (Purva, Focus group)*

EDUCATION

Implications for education ranged from involving ethnic health development workers to implementing changes in the curriculum to train professionals involved in diabetic

care. Involving the **ethnic health development workers** in education had multiple strengths such as bilingual language skills, a shared cultural background and it also released qualified professionals to look at other details rather than be involved in giving health education messages during a consultation due to time constraints as perceived by practitioners.

“Actually in this surgery, the GP sometimes, they’ve got many patients and haven’t got time to explain to them. We need our like care team workers should be there in the surgeries. Because GPs they, when they see they can’t explain everything. Then, there should be one setting of Umm... of our health care team worker should be there to explain and the patient go from GP should pass on to the care team.” (Hita, Focus group)

“...this why we actually involved the health, health development workers more, so that they were goin’ and givin’ in their own, in the patient’s home on a one to one and they spoke the language, something we didn’t do. And they would liaise back to us because obviously, they, they’ve language as well. They can speak English very well.” (Dhiren, Practitioner)

Madhur from Bangladesh suggested that having professionals from the same ethnic background especially to provide education on diet and lifestyle issues would help improve services since they would be more familiar with their cultural practices, values and belief systems as in the quote below:

“Even the dietitian sometimes, when I went to see the last time, this dietitian perhaps, she is not aware about Asian food habits. They need to keep one Asian dietitian who can help these people because I was asking her a question about the rice and she couldn’t. There are so many varieties of rice. So, people from Bangladesh, they believe, you

know the pre puffed rice, that is good for diabetes and I was asking her. She said, she had never heard about this.”

Malcolm, a practitioner also shared that it would be appropriate to have workers who are familiar with the culture to provide services since health promotion is the bedrock of diabetes care – *“I think it’s helpful to have workers who are fluent and conversant with the culture giving advice and I would say that’s the biggest help that since the bedrock of Diabetes care is health promotion then, it’s very much appropriate that information is given in a very culture specific, language specific way.”*

Networking with religious leaders and using the existing informal groups as effective avenues for health education were also suggested towards improving the educational programmes for minority ethnic groups with diabetes. **Drop in centres and satellite clinics** were the other possibilities that were suggested to improve service provision.

“Even at the General hospital, they can organize, they can allocate a room for the community. The community can go, there could be a drop in session to go whenever people have got a concern because lots of people might have got concerns.” (Madhur, Bangladesh)

“I think if we’re lookin’ at ten years from now I would say that we all have like satellite clinics. And if that was to happen and we had satellite clinics from what I’ve experienced or what I perceive to know about it is, these satellite clinics would be specifically targeted for and I don’t mean we should segregate them. I don’t mean that at all. But I think if you had South Asian ladies goin’ to satellite clinic on one given day, that education, the whole morning could be handed over to either the management of their Diabetes and then you could do workshops on health messages.” (Cheryl, Practitioner)

Inclusion of cultural practices by different ethnic groups in the **curriculum for training professionals** caring for diabetes was strongly recommended. Provision of

services for diabetes involved education on life style changes and practitioners quite often felt inadequate to educate patients since their knowledge on the socio cultural beliefs and values influencing health behaviour was often very limited. This imposed barriers to their understanding of health practices among different ethnic groups. Practitioners expressed that their current training didn't equip them sufficiently to address these challenges in their practice as explained by a practitioner in the following quote:

“I think really, from a health professional point of view, we, we truly don't know enough about their customs and (pause) and we're not aware enough of you know, how we can improve things. And I really think we should be gettin' taught to improve things. I, what the customs and cultures are of the South Asian community, what the differences are between male and female and not, I mean, over the years, picked up little things, but I mean that, that's just little things and I'm sure if all of us as health professionals knew a bit more about the different cultures, the different dialects, even cultures within cultures, we can then look and think “Well, O, Right. This is possibly why they're not complying with their treatment or why this is the barriers.” (Cheryl, Practitioner)

Conclusion

Risk perception is multidimensional (Park et al., 2001). Both the cognitive and affective domains in an individual significantly impact upon the individual's perception of risks and risk engagement. It therefore becomes necessary for practitioners to understand that they need to also factor in the influence of the affective domain in an individual while planning services to promote diabetes care and prevent long term risks in these individuals. Currently, the service provision predominantly caters to the cognitive domain and provides factual knowledge expecting patients to understand the risks from a purely medical perspective.

The National Service Framework (NSF) for diabetes – Standard 3 (Great Britain. Department of Health, 2002) was designed to empower people with diabetes recommending the use of structured models of education, personalised care plans and patient held or accessible records to be able to achieve this. The NSF that advocates concordance may be in conflict with the expectations on health care by older people who are familiar and comfortable with the traditional hierarchical model where the practitioners told them what to do.

Arguably, this poses major challenges with providing diabetes care towards risk prevention for older South Asians as demonstrated by the findings from this study. Concepts such as concordance and empowerment require participation by health care professionals and patients in the process of decision making. With issues around understanding diabetes as a disease, perception of its severity and the risks involved, barriers with language and literacy and the predominance of affect over cognition in risk perception, one needs to seriously examine if the empowerment model would be successful in improving the diabetic services for this population.

There were several valuable suggestions for practice development and education which would certainly be worth exploring. For practice development, suggestions ranged from ensuring a family oriented approach to increase risk awareness among South Asians given the premise that Type 2 diabetes has genetic predispositions. Provision of uniformly available services with wider access and increased cultural sensitivity was another recommendation. Ethnic monitoring and the use of ethnic health development workers as link workers were very strongly advocated both by South Asians and practitioners. In the area of education, networking with religious leaders, drop in centres and satellite clinics and inclusion of health related socio cultural practices of ethnic groups in the curriculum for training health professionals were suggested to improve health education and health promotion activities.

CHAPTER: 10

DISCUSSION

Risk Perception in Type 2 Diabetes – Development of a Conceptual Model

This chapter draws together some of the findings from this study with the concept of risk as its central concept. Risk perception has been investigated by social psychologists as ‘attitude’ since it involves beliefs about risk (Sjoberg, 2000).

In this study, using a qualitative approach, risk perception in the older South Asian population of the North East of England with Type 2 Diabetes was examined within the theoretical frameworks of the Health Belief Model (HBM) (Rosenstock, 1985), cultural theory (Douglas et al., 1982) and the Theory of Planned behaviour (Ajzen, 1991, 2002a; Ajzen et al., 2007). The HBM argues that health behaviour is dependent upon one’s health beliefs.

Perceived susceptibility and perceived severity together represent the perceived threat (risk) of a situation and prepare the individual to consider risk reduction strategies to avert that risk. The perceived benefits and barriers influence the individual’s attitude and behaviour towards implementing the strategies for risk prevention. Thus, the HBM incorporates several theoretical perspectives in addition to the component of risk perception (Groenewold et al., 2006). The original HBM has been expanded to include six factors predicting the possibility that an individual adopts a specific preventive health strategy (Glanz et al., 1997). The six factors described are perceived susceptibility, perceived severity, perceived benefits, perceive barriers, cue to action and self efficacy. Each of these six components are clearly described in the table on the following page. Transposing these factors to the findings of this study would result in a model on risk perception as outlined in Table 4.

Table 4: The Health Belief Model (HBM) and Risk Perception Model

HBM Concept	Application of the HBM	Transposition of HBM to Risk Perception in South Asians with Diabetes
Perceived susceptibility	South Asians' belief about the chances of acquiring long term risks related to diabetes.	} Risk awareness
Perceived severity	South Asians' beliefs about the seriousness of diabetes and its related risks.	
Perceived benefits	SouthAsians' beliefs about the effectiveness and value of the recommended health behaviours towards risk prevention.	} Ranking of risks (Visible Vs Invisible (Imminent Vs Non Imminent) (Personal Vs Social / Spiritual)
Perceived barriers	South Asians' beliefs about the potential negative consequences of adopting the recommended health behaviours towards risk prevention.	
Cues to action	Personal experience or past experience of caring for someone with diabetes related risks or environmental factors that motivate an individual to take action towards risk prevention.	} Risk Response
Self efficacy	Confidence in one's ability to successfully execute the recommended health behaviour.	} Risk engagement driven by one's locus of control.

As summarised in the table above, all the six components of the HBM had a direct relevance to findings from this study and related to either risk awareness or risk

engagement. The perceived susceptibility and perceived severity together represent the perceived threat of acquiring long term risks related to diabetes. This resulted in risk awareness involving cognition. The perceived benefits and barriers in relation to diabetes related risks led to ranking of risks that resulted in a “risk averse” attitude towards risks that were imminent and visible as against a “risk phillic” (Clarke, 2006) attitude towards risks that were invisible and non imminent. Cues to action and self efficacy represent factors such as personal experience with a diabetes related risk, presence of a family member as a health care professional, literacy, bilingual language skills and a strong internal locus of control along with motivation that resulted in risk engagement which was proactive. Risk perception in diabetes that led to health behaviour towards risk prevention was influenced by socio cultural and religious beliefs that were driven by affect rather than cognition and resulted in risk engagement which was reactive. This was also compounded by a strong external locus of control in this population.

Research around issues related to risk have been dominated by the psychometric paradigm which is rooted in psychology and decision theory (Rippl, 2002) and the landmark cultural theory of (Douglas et al., 1982). The psychometric paradigm that is commonly used to measure risk is based on two cognitive factors that influence an individual’s risk perception namely, the dread risk factor and the unknown risk factor (Slovic, 1987). This approach has been criticised for neglecting the socio cultural influences on risk perception given the understanding risk is socially constructed and is context specific. Decision Theory focuses on human activity where there are options to choose from and is concerned with goal directed behaviour in the presence of options (Hansson, 2005).

The cultural theory emphasises that it is not the individual ‘cognitive processes such as threats to health or feelings of uncontrollability’ (Dake, 1992) that influence risk perception but socially shared world views and cultural biases that determine the way an individual perceives risks. Attitudes and decisions about risk are based on the expectations and value systems of the distinctive group that people belong to and identify with (Tansey et al., 1999). The psychometric approach is more inclined

towards analysing the technical aspects of risk as against the cultural theory approach which seeks to analyse the social or perceptual aspects of risk (Kasperson et al., 2001).

The technical approach to risk measures risk (R) in terms of magnitude (M) and the probability of exposure (P) and arrives at an equation, $R = PM$ which advocates reducing the largest risks to which a population is exposed. The rational choice in such situations is predominantly about safety guided by the 'utility principle' which is central to economic rationalisation (Tansey et al., 1999). The psychometric paradigm is an appropriate approach to be applied to human health risk perception and suggest the development of psychometric scales that are inclusive of a list of hazard items of risky events, practices, response to different hazards and evaluation of each item on the scale to identify characteristics that influence risk perception assuming that risk is inherently multidimensional (McDaniels et al., 1997).

Undoubtedly, psychometric measurements influence risk identification, risk perception and decisions around risks based on risk ranking. However, there is an increasing approval of the fact that risk perception is a social phenomenon that needs to be studied within a social context. What one perceives as risk and the amount of risk one chooses to take depends upon their cultural adherence and social learning (Oltedal et al., 2004).

Risk also has a political dimension with subjective features in that it is a 'function of fairness considerations such as trust, liability, distribution and consent' (Tansey et al., 1999). The psychometric approach is centred around cognitive processes and is therefore not able to address the political dimensions of risk which involve affect. The cultural theoretical approach to risk perception expounds the reasons for politicisation of some types of risk as against others which are accepted within social norms. It aims to explain how risks are perceived and managed and the socio cultural aspects that govern them.

An important form of cultural theory is the Grid - Group typology (Douglas et al., 1982). Group and grid are the two essential dimensions within which social interactions occur. Group refers to whether an individual is a member of bonded social units and the influence of the group's activities on the individual. Grid, on the other hand represents the extent to which a social context is regulated and restrictive in relation to the individual's behaviour. Higher the grid (social regulations and restrictions that are expected to be adhered to), behavioural options become limited. As the grid relaxes, the behavioural options increase with increasing opportunities for negotiation. There are interactions between the individual and the environment that is guided by the dimension an individual belongs to along with his social relation. The Grid – Group analysis placed on a two axis system from low to high representing social environments resulted in four worldviews in relation to risk perception as demonstrated in the following model.

The four worldviews are termed as individualistic, egalitarian, hierarchical and fatalistic. The individualistic worldview is characterized by low group and grid. Egalitarians are members of high group and low grid cultures, the hierarchical way of life is defined by high grid and high group and the worldview is fatalistic with high grid and low group (Oltedal et al., 2004).

		GRID	
		High	
		Fatalistic	Hierarchic
		Low	High
GROUP	High		
	Low	Individualistic	Egalitarian
		Low	

Fig. 15 Group – Grid Model of the Cultural Theory

(Douglas et al., 1982)

People who are individualistic perceive risk as an opportunity as long as it does not interfere with their freedom. They fear that the social requirements might curtail their individuality and hence prefer not to interact socially.

Individuals who are egalitarian are socially concerned, tend to view expert knowledge with scepticism and hence suspect that authority by experts might be misused. They have strong beliefs in social equality and will therefore generally oppose any risk that will inflict irreversible consequences on their society or future generations.

People who are hierarchic members of the group emphasise “natural order” (following social regulations and restrictions as laid down by society as in women not being unaccompanied while going outdoors, fasting during Ramadan etc) of the society and work towards preserving the same. Unlike the egalitarians, they respect and trust the experts. They tend to deal with the risk as long as decisions about these are made and justified by experts.

Individuals who are fatalistic are quite indifferent about risk and would therefore prefer to be unaware of dangers since they are convinced that those risks are unavoidable. They choose to deal with whatever problem comes along and try not to worry about risks about which they feel that they have no control over.

If one were to place South Asians with Type 2 Diabetes into this Grid – Group analysis in relation to their risk perception in general, they would mostly fit into the Fatalistic group. Factors such as resilience towards diabetes related risks and the external locus of control around fate and luck as described in the earlier chapter would predispose them to this category.

There were a few participants who would represent the hierarchic group who also believe in adhering to the socio cultural and religious expectations but engage with risks as long as decisions around risks are guided by experts (health care professionals). This was characteristic of those who were literate, bilingually competent, had a family member who was a health professional, and were motivated with a strong internal locus of control and. They not only respected and trusted experts but also actively sought their support and decisions around risk prevention like Madhur for instance.

Individuals tend to adhere to different cultures in different situations (Oltedal et al., 2004). An individual could be hierarchical at work and individualistic at home and this is difficult to be assessed using a questionnaire. Interestingly, those who were fatalistic in this study also had some features of hierarchic members in that they sought decisions and trusted experts but didn't engage in risk prevention with that knowledge and expertise. Instead, the responsibility towards managing those risks was shifted to the experts applying the principle of external locus of control.

The findings from this study have reinforced the significance of studying health related risks in particular within the socio cultural context of the individual. South Asians ranked risks (Health versus Social, for instance) and chose to ignore risks that weren't visible or imminent. The cultural theory doesn't address issues related to ranking of risks, the influence of locus of control and risk engagement within its four world views and this study adds valuable information on these aspects within the world views of the cultural theory.

The cultural theory also has its limitations. Using cultural theory as a theoretical approach with questionnaires will not be able to identify mixed adherences unless the same questionnaire is designed to address risk perception in multiple contexts. Cultural adherence is not an inherent characteristic. It would be preferable to choose respondents depending on their adherence to particular institutions with distinctive grid and group characteristics if questionnaires are to be used (Marris et al., 1998). Using cultural theory to study risk perception has been criticised for the following reasons (Oltedal et al., 2004). If culture is seen as something preset, it would help to explain how risks are perceived as a culturally learned phenomenon. With culture being mobile, it is probably risk perception that results in cultural adherence. The lack of clarity on the meaning of culture makes it difficult for the theory to be operationalised which is probably why the theory doesn't sufficiently explain the variances in risk perception.

The Theory of Planned Behaviour (TPB) has been widely used in understanding diverse health related behaviours such as exercising, adhering to a low fat diet and other life style related issues. According to the Theory of Planned Behaviour, human action is influenced by three major variables as follows.

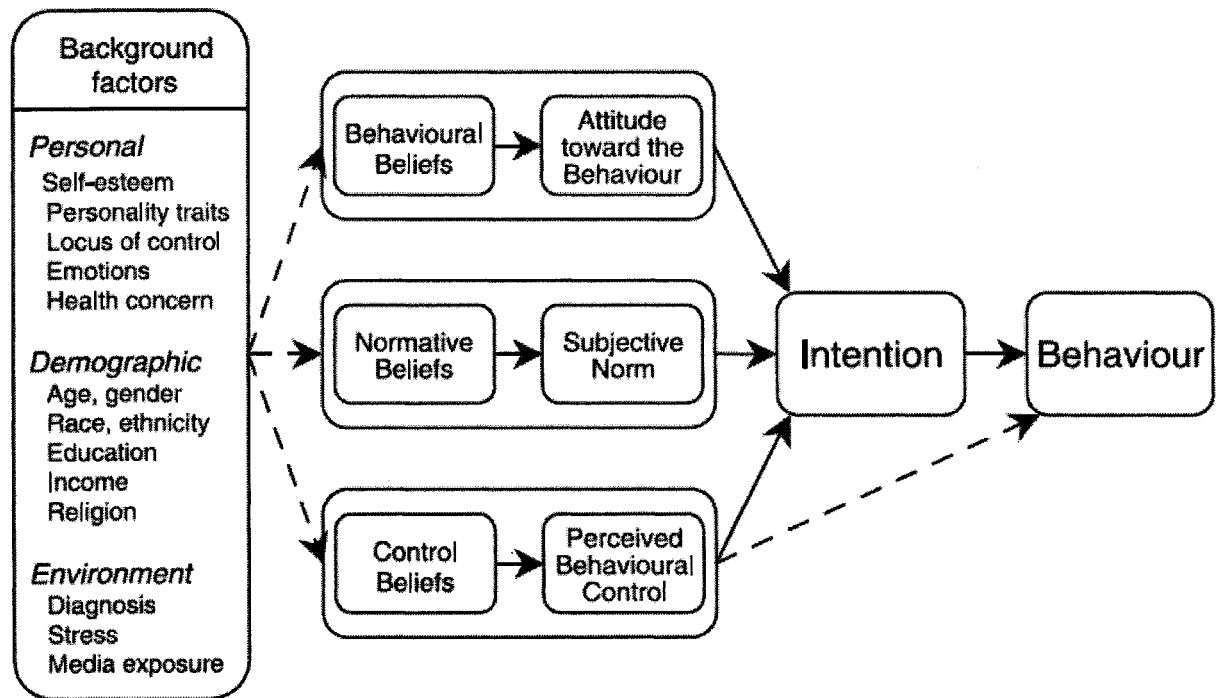


Fig. 16 Theory of Planned behaviour Model (Ajzen et al., 2007)

The fit and relevance of this model to the findings of this study have been outlined in the table in the following page.

Table 5: Theory of Planned behaviour and Risk Perception Model

VARIABLES OF THE THEORY OF PLANNED BEHAVIOUR	DESCRIPTION	RISK PERCEPTION AMONG OLDER SOUTH ASIANS WITH TYPE 2 DIABETES
Attitude towards the behaviour (Behavioural Beliefs)	Favourable or unfavourable evaluation of the behaviour	Understanding of diabetes, personal experience with risk, the lack of immediacy and visibility of risk and perceived severity of diabetes (Cognitive Domain)
Subjective Norm (Normative Beliefs)	Perceived social pressure to perform or not perform the behaviour	Socio cultural / religious expectations (Affective Domain)
Perceived behavioural control (Control Beliefs)	Perceived capability to perform the behaviour	Locus of control (Internal & External)

Attitude towards behaviour is believed to be determined by beliefs about the consequences of adopting that behaviour. In this study, attitude towards diabetes and its related risks were based on the South Asians' understanding of diabetes, immediacy of the risk, visibility of the proposed risk and perceived severity of the illness.

For instance, if an individual's belief was that diabetes was caused due to the cold weather and lack of sunshine in the UK, he / she chose to travel to their home country for extended periods of time and also discontinued medication since the perception was that the diabetes had disappeared while they were back home. This attitude affected the desired health behaviour of adherence to prescribed medication and prevention of long term risks. The degree of perceived risk influences risk perception—the extent of seriousness that is attributed to the risk. When the risk is perceived to be high, the individual seeks measures to reduce the risk or avoid the risk if possible. Perception of severity with their diabetes was dependent on the number of tablets that one was taking, presence or absence of insulin therapy, frequency of hospital appointments and the type of services accessed. This was also largely attributed due to the lack of visibility and immediacy of the proposed risks.

Normative beliefs refer to the perceived behavioural expectations of significant referent individuals or groups such as the individual's family or religion as in the case of South Asians with diabetes. The normative beliefs along with motivation to comply with the expected behaviour determine the behaviour. Data from the study clearly revealed that religious requirements such as fasting during Ramadan were strictly adhered to even without consulting health professionals for fear of being advised not to comply with those requirements because of the health risks involved. The socio cultural and religious factors described in Chapter 6 explicitly describe the influence of perceptions on ageing, gender and family dynamics on risk perception. There was identification of priorities and ranking of risks that people exercised internally. For example, when faced with having to make choices between the risks involved such as suboptimal diabetic control versus causing a social offence, the risk preference was to comply with hospitality gestures of eating sweets that were offered during social occasions at the risk of poor diabetic control. The risks at hand were weighed or ranked and people were generally inclined towards taking those risks that were not visible or imminent (Health risks) and were averse to those which were visible and imminent (Social risks).

Control beliefs deal with the perceived presence of factors that can facilitate or impede performance of behaviour. This was associated with the locus of control influencing risk awareness and risk engagement in this study. An individual's perceived locus of control and their ability to be in control of the situation guides them either to take or avoid a particular risk. Individuals with an internal locus of control viewed themselves as being responsible for the consequences of their actions as in the case of Daanaa. On the contrary, individuals with an external locus of control, viewed things like fate and luck as being responsible for the consequences despite their actions as in the case of Haala for instance.

The study demonstrated that the locus of control among South Asians was largely external and the response to risks varied from depathologising the illness to resilience. Individuals who were educated and bilingual with the presence of a health care professional as their family member had a strong internal locus of control that influenced their awareness of risks and engagement with risks related to diabetes. They were motivated and proactive with risk engagement as discussed in Chapter 8.

Findings from the study as discussed in detail in Chapters 5 – 8 led to an innovative conceptual model on risk perception among older South Asians with Type 2 Diabetes as outlined in the following page.

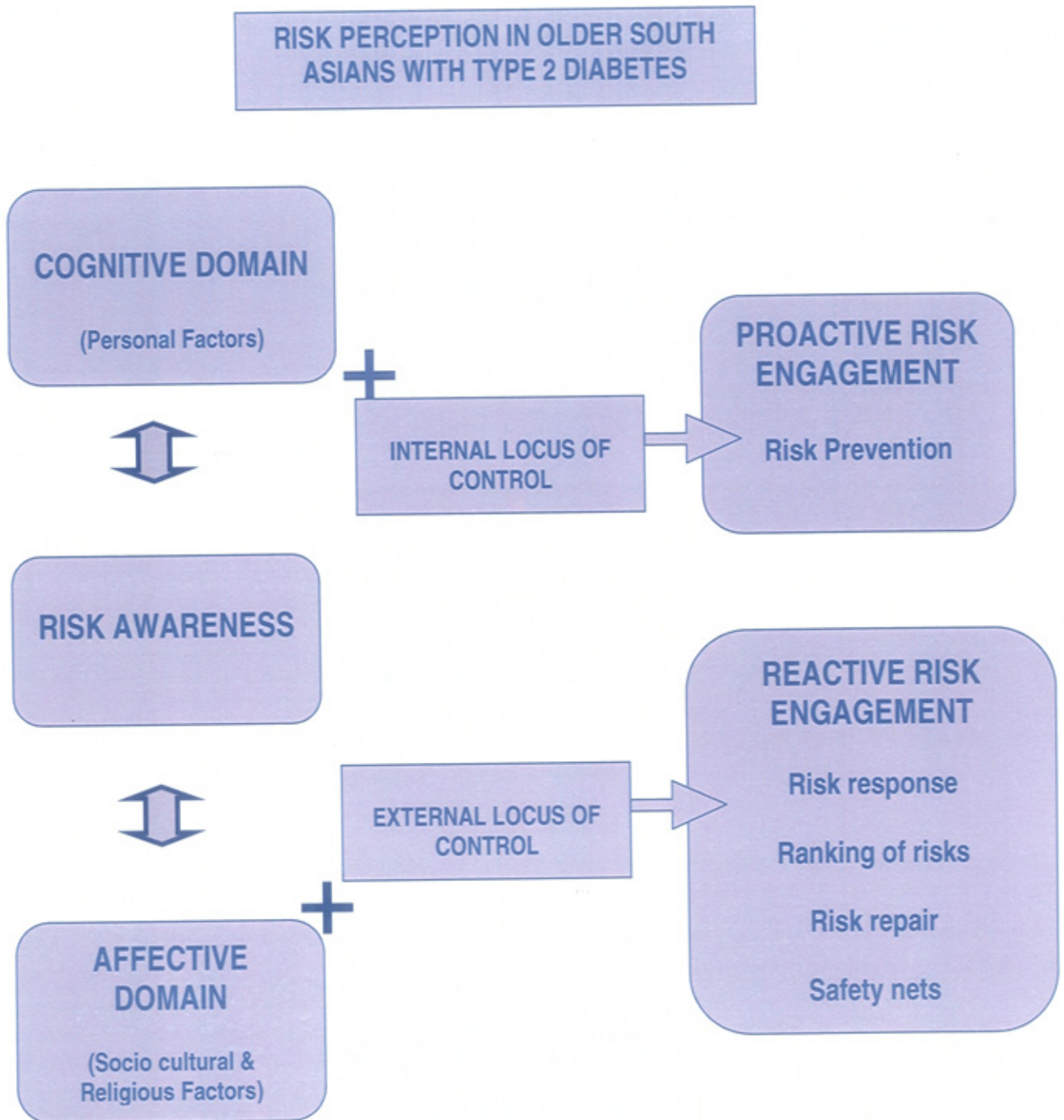


Fig. 17 – Older South Asians with Type 2 Diabetes: A Model on Risk Perception

Factors such as understanding of diabetes, perceived severity of diabetes, personal experience with risk, immediacy and visibility of risks represent the cognitive domain in an individual with diabetes. The degree of perceived risk influences risk perception– the extent of seriousness that is attributed to the risk. When the risk is perceived to be high, the individual seeks measures to reduce the risk or avoid the risk if possible. Perception of severity with their diabetes was dependent on the number of tablets that one was taking, presence or absence of insulin therapy, frequency of hospital appointments and the type of services accessed. This was also largely attributed due to the lack of visibility and immediacy of the proposed risks. These beliefs were found to be operational in an individual's cognitive domain among the older South Asians with Type 2 diabetes. The socio cultural and religious factors such as spirituality, adherence to cultural norms, social expectations and priorities in an individual's life operated from the affective domain. These in turn influenced risk perception which resulted in risk awareness. Risk awareness led to either proactive or reactive engagement with risks and was influenced by either internal or external locus of control as discussed below.

Individuals with an external locus of control, viewed fate, luck etc as being responsible for the consequences despite their actions. The study has demonstrated that the locus of control among South Asians was largely external. The external locus of control led to consequences such as denial, depathologising of diabetes and an attitude of resilience and powerlessness. Socio cultural and religious factors beliefs along with external locus of control resulted in reactive risk engagement through risk responses, ranking of risks, risk repair and creating safety nets as discussed in the Chapter 8.

Risk awareness involving the cognitive domain, when influenced by internal locus of control resulted in proactive risk engagement among the South Asians with diabetes. Individuals with an internal locus of control viewed themselves as being responsible for the consequences of their actions and consequently sought to proactively engage with risks and worked towards risk prevention as in the case of Madhur. The specific variables that influenced internal locus of control which in turn resulted in risk

awareness leading to proactive risk engagement were literacy, bilingual language skills, personal experience with risk, motivation and the presence of a health care professional within their immediate family.

Individuals made decisions about a particular risk depending on their past experience with a particular risk rather than depend on a complete understanding of the risk in its entirety and engage proactively in the preventive behaviour that is recommended. Both these factors were very apparent in this study. This is similar to the description of factors such as prior knowledge of specific risk, locus of control, degree of perceived risk and access to information that individuals normally use in conceptualizing 'risk' for themselves among consumers in the marketing industry (McGregor, 2006).

Risk perception and risk communication have largely focused on individual cases of risk taking. Therefore, risk communication aims at changing individual behaviour and addresses individual risks by providing information about the specific risk and the recommended behaviour and activities in order to facilitate the desired behavioural change. This study focused not just on individual risk behaviour but on risk behaviour among older South Asians with diabetes. Findings from the study have clearly demonstrated that risk awareness and risk engagement in diabetes among older South Asians are significantly influenced by socio cultural and religious factors involving the affective domain and external locus of control that result in reactive risk engagement.

This in turn has a significant bearing on the health promotion strategies and services that are planned towards behavioural change and life style modifications that are essential to prevent long term risks that are related to diabetes. A risk framework which analyses individual risk taking behaviour in terms of poor outset conditions, lack of reasonable options, hope and liability to disinformation rather than focusing on perceived benefits that outweigh the risks has been made available (Hayenhjelm, 2006). The author also argues that explanations such as individual risk taking behaviour alone do not sufficiently explain individual risk taking in a meaningful way.

Risk taking that results from vulnerability in individuals could be the consequence of their loss of control over the situation or the inability to make choices within the context that they are in. It could often be due to lack of alternatives. In this situation, they are not left with much choice but to contend with the predetermined conditions that already exist which they have no control over. Examples of this from this study would be the gender issues in relation to choosing healthier cooking options for a woman with diabetes as in the case of Baqueer's wife (the healthier cooking options were considered only after Baqueer was diagnosed to have diabetes in spite of his wife having been diagnosed to have diabetes a year or so before his diagnosis was made) or societal values such as hospitality that expect the individual not to turn down sweets that are offered while visiting someone as in the case of Galina.

Another example is the non availability of an interpreter during a medical consultation unless previously booked and the preference of health care professionals to use the professional interpreters as against a family member who accompanies the patient. Risks from vulnerability need to be understood in terms of individual choices and the lack of alternatives or information that an individual is faced with. Since these kinds of risks do not fit traditional ways of risk taking (loss versus benefits) these risks may need social and political attention rather than individual advice.

Individuals take risks from having hope or positive expectations of a possible but uncertain beneficial outcome. Hope can significantly alter one's choice of options. Individuals tend to choose the option that offers hope even if that option only offers a slightly better outcome compared to their present situation. In case of diabetes and risk engagement with the South Asian Muslims in particular, they were often found to be acting from the hope that was based on their religious values and beliefs. The hope that they held very strongly was that God was in control of whatever happened in their lives and therefore it was considered to be very important to please Him by following all the religious requirements (eg. Fasting during Ramadan, going on 'Hajj' etc). This resulted in individuals taking risks such as fasting without seeking medical advice while on insulin, changing medications around their meal times during Ramadan in

the hope that God will look after the consequences that came along. Understanding the interaction between the above elements helps us to see risk taking as clinging to hope rather than being irrational and irresponsible. The hope that was adhered to was that their lives were preordained and that God was in control of whatever happened to them and that was very central to the way risks were perceived.

Both false information and limited access to information can influence risk taking behaviour especially in a vulnerable individual. Limited access to information primarily due to language barriers was an issue with risk perception in the South Asian population with Type 2 diabetes. Both practitioners and South Asians expressed difficulties with this barrier that often came in the way of understanding religious beliefs and cultural practices that affected diabetes management. This also made communication more challenging and the use of interpreters to address this issue had its own limitations as discussed earlier. South Asians being an ethnic minority group in the UK and also being more vulnerable to developing Type 2 diabetes due to their genetic make up, dietary habits, low socio economic status and sedentary life style need to be empowered about the risks that are associated with diabetes and ways to prevent those risks. Therefore, good risk communication becomes essential to disseminate information in order to empower people.

It was observed from the findings of this study, that the degree of knowledge and risk awareness related to diabetes was limited and people perceived diabetes to be caused by cold weather, lack of sunshine, fate, excessive consumption of sweets as opposed to a physiological deficiency of insulin in their body. This in turn had a significant bearing on how risks were perceived and engaged with. It poses significant implications for practice in terms of identifying and promoting appropriate strategies to enhance knowledge. Information not only needs to be made available but also made accessible given the language and literacy barriers within the South Asian community. The role of using the mass media in different languages and employing additional ethnic Health Development Workers who share the same cultural background for interventions on health promotion within the health service are some of the options that could be explored.

Our current knowledge on risk perception in clinical settings is diverse and complex. It is evident from the findings of this study that both South Asians and their practitioners have varied perceptions of the same risk which is influenced by the magnitude and consequences of the risk, and individual characteristics such as a desire for control, past experiences and the personal belief system. Framing of risk information is yet another significant factor that influences decision making in relation to taking risks (Walter et al., 2002). The lay person's risk perception is much 'richer' when compared to sophisticated risk assessments done by the experts (Slovic, 1987).

The paradigms of illnesses between lay people and practitioners have been proven to be different. Such variations and incongruence can adversely influence patient compliance, satisfaction, utilization of health care services and response to treatment since they are unable to understand and interpret each others' "language" regarding the illness (Cohen et al., 1994). Perspectives on risk between South Asians and practitioners are quite varied as significantly demonstrated by the data from this study in Chapter 7.

The dominant model of disease even today is the biomedical model that proposes diseases to be due to deviance from the norm of somatic variables (Cavan, 2001). It exclusively deals with the somatic dimension and is not inclusive of the psychological, social and behavioral dimensions of a disease. With chronic illnesses such as diabetes, the concept of health risk is no longer external to the self as a result of interactions between the individual and his environment alone (Ogden, 1995). It is instead very inclusive of the self within the individual who is faced with the need to take control and make choices in managing health related risks since they largely involve life style issues. There are several factors that influence the conceptualization of risk among different groups of people.

A Paradigm Shift in Diabetes Management – Its relevance for South Asians in the UK

With the exponential increase of diabetes world wide, all European countries, the International Diabetes Federation Europe and the World Health Organisation have made a declaration to optimise the management of care for patients with diabetes that is aimed at decreasing the risk of long term complications (World Health Organization et al., 1990). Self care behaviour has been identified as the cornerstone of effective diabetes management by integrating dietary changes, physical activities and medications inclusive of insulin into one's daily routine.

Traditional models of diabetes care relied on individual compliance. This often led to poor diabetic control. With changes in health care policies and the modernisation of the NHS, there was a paradigm shift towards the development of the patient empowerment approach (Henshaw, 2006). The empowerment approach recommended concordance as against compliance. While compliance embodies a traditional model of prescriptive care, concordance emphasises the importance of respect for mutual goals between the health care professional and the patient in addition to signifying a negotiated agreement between them. Development of such a “therapeutic alliance” (Adisesiah, 2005) where health care professionals share their knowledge and expertise that enable patients to make informed choices about diabetes care is being increasingly seen as the way forward. National Service Frameworks were drawn up in accordance with this paradigm shift for various chronic diseases inclusive of Type 2 Diabetes.

On the contrary, patients often feel judged and blamed for not following the advice given by their health care professionals in managing their diabetes. This often fosters conflict and tension between patients and practitioners (Anderson et al., 2005). The concept of empowerment has many related variables due to the obvious lack of standardisation. However, variables such as ‘patient centered approach’, ‘collaborative care’ and ‘Self Management Education’ (Henshaw, 2006) within the concept of empowerment all relate to a process that gives people with diabetes more

control of their own lives. A significant element of empowerment is 'self efficacy' which in this study relates to the locus of control based on the Health Belief Model. It has been widely documented that empowerment and 'self efficacy' are directly proportionate to each other (Bandura, 1997). Risk perception being predominantly driven by affect and the external locus of control among the South Asians with diabetes in this study, practitioners will be faced with the challenge of promoting the concept of empowerment and 'collaborative care' in providing services towards risk prevention and risk management.

The concept of concordance that advocates the empowerment model which would facilitate informed decision making and self management of diabetes needs to be critically reviewed especially for minority ethnic groups with a chronic disease such as diabetes. Health care professionals adopting the discourse of empowerment without critical review and a balance may lead to a false sense of security that everyone with a chronic disease will be completely empowered and result in a 'myth of empowerment' (Paterson, 2001). A systematic review on empowerment, diabetes and the National Service Framework (Henshaw, 2006) has clearly shown that interventions effectively empower individuals only when based upon individual focussed goal setting, coping skills and problem solving strategies. For practitioners to be able to achieve this with the South Asians, they would need to be adequately knowledgeable regarding the South Asians' personal, socio cultural and religious beliefs and the role of locus of control in relation to risk perception in diabetes. The study therefore, has made significant contribution in terms of providing information on all these variables in relation to risk awareness and risk engagement in this population.

An exploratory study that aimed to explore the relationship between attitudes towards self care behaviour, subjective norms, behavioural control, behavioural intentions and actual self care behaviour in patients with Type 2 Diabetes at Malta (Gatt et al., 2008) using the Theory of Planned Behaviour reports that attitudes, subjective norms and perceived behavioural intention were important predictors of intent to carry out self care behaviour in individuals with Type 2 diabetes. The study also demonstrated that perceived behavioural control was one of the key determinants of self care in people

with Type 2 diabetes. The authors strongly recommend that health care professionals must factor this in while recommending self care activities to these patients. To extend this further in relation to this study on risk perception, it would be similarly valuable for practitioners to assess the perceived behavioural control in relation to prevention of long term risks related to diabetes while caring for South Asians with Type 2 diabetes.

Similar to the findings from this study, other studies have also reported that the self care behaviour which the participants in their study were highly inclined towards was taking medications that were prescribed and were least inclined towards physical activity and dietary adherence (Gatt et al., 2008). The performance of behaviour is dependent upon the extent to which resources are believed to be present and are perceived to facilitate or impede the performance of the behaviour (Ajzen, 2002b). This is clearly apparent from the findings of this study as in people attributing their lack of exercise being due to lack of culturally sensitive venues, language barriers and the controversies with using family members for interpretation during a medical consultation and the family dynamics that interfered with dietary adherence and risk prevention.

It is therefore certainly evident from this study that empowering older people with diabetes to manage their diabetes and work towards risk prevention has multiple challenges. The successful learning of any health related behaviour is an ongoing process that requires a sustained relationship between practitioners and patients. The empowerment model as against the traditional medical model of care is geared towards facilitating a joint decision making process, educational interventions, positive psychological well being (participatory care) and positive behaviour change that would ultimately promote good diabetes control (Meetoo, 2004) and prevent long term risks.

Empowering an individual can be influenced by psychological, social and economic variables. Specific psychological variables may include motivation, perception of control and coping style. Another useful concept to consider in this context is the

locus of control. External locus of control can negatively influence an individual's coping style which in turn would adversely affect the desired health behaviour (Watt et al., 2008).

Challenging as it may seem, the empowerment model of diabetes care is undoubtedly vital in diabetes care. Practitioners need to blend information giving, psychological support and education with cultural sensitivity for the model to be effective. The conceptual model on risk perception from the findings of this study has given significant clarity on an ambiguous concept such as risk perception among South Asians with diabetes. It is within these trajectories that an understanding of the various factors influencing risk perception in this population becomes crucial for practitioners. Significant progress is being made with diabetes research towards preventing long term risks by combining therapeutic interventions with empowerment.

The role of cognition is vital in the empowerment model that emphasises self management and educational interventions towards long term risk prevention. However, this study has also demonstrated that the role of affect is significant with the way South Asians understand and engage with diabetes related risks. When there is incongruence between cognition and behaviour where individuals are aware of the risks, know the risks are not favourable and yet engage in the risky behaviour (eg. Smoking) the role of affect leading to engaging with the risky behaviour is being increasingly evidenced (Loewenstein et al., 2001). This is very similar to findings from this study where people with diabetes chose to engage with risky behaviours such as indulging in sweets, missing medications and hospital appointments despite risk awareness when driven by affect. There is a growing evidence to support that for many behaviours, affect is more predominant than cognition in the prediction of behavioural intentions. As a result, there is an increasing emphasis that research involving attitude needs to measure both the cognitive and affective components contributing towards attitudes (Ajzen et al., 2005).

Key Summary

The aim of this study was to develop a conceptual model on risk perception among older South Asians with Type 2 Diabetes in the United Kingdom. Data collected for this purpose using an evolved Grounded theory approach with its theoretical foundations drawn from Symbolic Interactionism resulted in a conceptual model (Fig.16). Risk perception among older South Asians was interpreted in terms of risk awareness and risk engagement. Risk awareness was influenced by factors from within the cognitive and affective domains that resulted in risk engagement. Risk engagement was proactive if risk awareness was present and the locus of control was internal. Risk awareness involving the affective domain resulted in reactive risk engagement through risk response, ranking of risks, risk repair and creation of safety nets when influenced by external locus of control.

NSF recommendations towards empowering people with diabetes is based on the premise that when individuals are given the freedom to choose and opportunities to reflect would be willing and able to set appropriate goals for their diabetes management. This also demands that individuals take responsibility for the decisions that they make. Understandably, the whole concept of empowerment will be very challenging for both practitioners and older South Asians with Type 2 Diabetes given the predominant role of affect and external locus of control influencing risk perception and subsequent behaviour towards risk prevention. However, considering factors such as literacy, bilingual skills, the awareness on healthy eating and healthy lifestyle (weight reduction and physical activity), the concordance model may be more relevant and effective with the younger South Asians in the UK. Definite conclusions about this are not possible about this from the findings of this study since this wasn't within the scope of this research.

Conclusion

Chronic diseases such as diabetes could cause a disruptive experience and impinge upon the individual's self concept especially if its arrival was unanticipated. It also has the potential to disrupt relationships and day to day affairs leading to dependence and therefore requires support to manage it long term (Bury, 1982).

An underestimation of personal health risk could reduce the motivation for a change in behavior- dependent risk factors and could decrease compliance with medical prevention strategies (Kraywinkel et al., 2007). Primary prevention has large potential benefits for diabetes related risks such as cardiovascular risks. Adequate risk perception is an important step for the change of risk related lifestyles. It is therefore important to highlight the South Asians' understanding and risk perception in relation to Type 2 Diabetes for service providers to become aware of the lay understanding of risk perception in chronic diseases such as diabetes.

Health care sciences such as Medicine are inclined towards 'professional dominance' and the 'monopoly of medical knowledge' (Lawton, 2003). This leads to patients not being part of the decision making process contrary to the contemporary emphasis on participatory health care by empowering patients. The strength of an individual's social network and the support systems available are very essential to be understood in the management of chronic disease. This is very crucial for South Asians with diabetes for whom family and their social networks are significant. There are several factors that influence the way in which a chronic disease is experienced at the macro contextual level. At the micro contextual level, it is worthwhile to focus on familial and other inter personal relationships while managing chronic disease in order to understand how illness is 'lived' and negotiated in peoples' every day lives (Lawton, 2003). This is significant in the management of an individual's diabetes – The individual may be highly motivated to comply with the treatment and life style changes but may not be able to make it a reality due to the intricacies within the family dynamics such as having to cook and also eat what is preferred by the men in

the family or unable to exercise due to her role and associated responsibilities as a wife and mother in the South Asian context.

Both the cognitive and affective domains interact with each other through the dynamics of locus of control in perceiving risks related to diabetes among the older South Asians and led to risk awareness. Risk engagement that resulted from risk awareness was either proactive or reactive and was dependent on whether the locus of control was internal or external. The relevance of the concordance / empowerment model of diabetes management that advocates self management and aim towards risk prevention in the light of the findings from this study where affect and the external locus of control play a significant role in risk engagement needs further exploration.

Since the management of diabetes and prevention of long term risks involve life style changes that are heavily dependent upon the socio cultural and religious factors along with family dynamics within the South Asian context, it becomes imperative for practitioners to become aware of these issues and their impact upon risk perception in South Asians with diabetes in order to provide services that are culturally sensitive and relevant in addition to keeping pace with the recommended national standards of care for diabetes.

CHAPTER: 11

SUMMARY & RECOMMENDATIONS

Contribution to Knowledge

Findings from the study have clearly revealed that risk perception does not necessarily involve only risk awareness or understanding of the risk but is also inclusive of risk engagement behaviour. Thus, risk perception is a more comprehensive concept that accounts for both risk awareness and risk behaviour. Awareness of a particular risk does not always influence individuals to adopt risk prevention strategies. Engaging with risks is subjective and context specific. The study has clearly demonstrated that the South Asians in this study engaged with diabetes related risks either proactively or reactively which was strongly driven by their individual locus of control. Interesting concepts of risk engaging behaviour such as risk repair and creating safety nets have emerged as an outcome of this study which have previously not been documented in the risk literature. Ranking of risks in the process of risk engagement, particularly with health related risks using a qualitative approach has also been possible as an outcome of this study.

The conceptual model that has evolved from the findings of this study has enhanced our understanding on risk perception in this population. The role of both the cognitive and affective domains in influencing risk perception is apparent. The affective domain being predominant in comparison to the cognitive domain has significant implications in the planning and provision of services to minority ethnic groups. The western rational model of medicine and health care may not be very relevant since the overall emphasis in such a model is the use of cognitive domain where patients or service users are expected to access information and make rational choices.

The concordance and empowerment model of diabetes care emphasises self management and mutual goal setting towards good diabetes management and subsequent risk prevention. The role of cognition is paramount in such a model in

understanding long term risks along with a strong internal locus of control to work towards risk prevention. This study has clearly demonstrated the role of affect and external locus of control in risk engagement among older South Asians with Type 2 Diabetes. Therefore, the need for careful scrutiny and evaluation of the concordance and empowerment model of diabetes care for minority ethnic groups such as the South Asians who engage with diabetes related risks reactively is reinforced.

Health related risks do not generally fit traditional ways of risk taking (loss versus benefits) and this has been clearly demonstrated in the way people ranked risks, driven by the need for socio cultural and religious adherence rather than personal loss or gain. It is therefore essential to understand risks from vulnerability – (increased vulnerability of developing Type 2 diabetes because of the genetic predisposition and the socio cultural / religious expectations over which people may not have control even as described in the Group – Grid model of Cultural Theory (Oltedal et al., 2004) in terms of lack of alternatives for an individual while developing services for diabetes care. Therefore, health related risks may need social and political attention to address some of these complexities. Research that explores health related risks to guide policies and service planning in line with the National Service Frameworks for any chronic disease must be encouraged and facilitated.

Factors such as literacy, bilingual skills, motivation and internal locus of control have been identified as factors that promote proactive risk engagement. It would therefore be appropriate to capitalise on these factors to promote lifestyle practices from a very young age among immigrant South Asians given their increased vulnerability to Type 2 Diabetes. Events such as diabetes awareness camps conducted at schools may yield positive outcomes. The presence of a health care professional within the family also promoted proactive risk engagement. This could possibly suggest that involving more ethnic health development workers who are familiar with the socio cultural and religious practices could help integrate these factors into diabetes care at least at the primary care level to promote risk prevention.

Significant light has been thrown on the socio cultural / religious factors and gender variations in risk perception among older South Asians with diabetes. Risk perception has been explored in depth from both the service users and service providers which has facilitated the understanding of gaps that need to be bridged. This would enhance the existing knowledge base and provide valuable input towards service provision and practice, education and policies for diabetes care among minority ethnic groups and South Asians in particular. Previous research on Patient – Practitioner variations has been in the Caucasian group (Cohen et al., 1994). This study has explored South Asian – Practitioner variations in risk perception related to diabetes in a minority ethnic group living in a western society. It has also highlighted the need to equip practitioners with some training on socio cultural and religious beliefs, values and practices of the different ethnic groups that they are expected to care for especially where life style changes need to be advocated.

Implications for Practice, Education and Policy

Much of the literature that is available emphasizes problems associated with having diabetes from the perspective of health professionals, rather than from the perspective of the person living with the illness (Koch, 2000). Lack of clear recognition of a future threat has been linked to poor compliance with diabetes treatment (Rosenstock, 1985). The information that we have from this study helps us to understand the difficulties and issues that the South Asians have in managing their Diabetes and understand the risks related to Diabetes from a socio cultural perspective.

This section describes the implications that are relevant to practice and service provision, education and changes in relation to policy that emerged from the findings of both data sets, older South Asians with Type 2 Diabetes and practitioners as an outcome of this study.

Practice and service provision

Most South Asians who participated in this study were very satisfied with the services that they received for their diabetes care. They were able to compare the services with their country of origin and expressed satisfaction with the services being delivered with quality and free of cost in contrast to most health care services having to be paid for back home. With regard to practice and service provision both practitioners and the South Asians had much to offer by way of suggestions for the future (Chapter 9). The dynamics of managing Type 2 diabetes being family oriented with all the lifestyle changes required, it would not suffice to just deal with it on a one to one basis. A family oriented approach instead may be the way forward considering the significance of the affective domain involved in risk perception in this population.

The study has clearly demonstrated the need for input into the cognitive domain as well. Issues such as lack of language specific information on services available and access to those services need to be addressed. In terms of service provision, services needed to be more uniformly available with wider access and increased cultural sensitivity. Information not only needs to be made available but also made accessible given the language and literacy barriers within the South Asian community. The role of using the mass media in different languages and employing additional ethnic Health Development Workers who share the same cultural background for interventions on health promotion within the health service are some of the options that could be explored.

Facilities such as an annual review for early detection of diabetes related risks aren't available in all the GP surgeries at present. Some patients were seen to by the GP while others were referred to the Regional centre and this also led to misconceptions about the severity of one's diabetes. There was also a lack of standardisation in the way these services were run especially in terms of follow up. Coordination of the available resources would enable optimization and efficient utilization in addition to making the services more streamlined. Attempting to create new services each time is reinventing the wheel rather than achieving its purposes.

The need for ethnic monitoring by health professionals is another area that needs to be revisited. Health promotion is the bedrock of diabetes care. The model of involving ethnic Health Development Workers in GP surgeries as link workers to provide services and education featured from the interviews with practitioners. The commonality of their background, language and a shared understanding of socio cultural and religious values, family dynamics and lifestyle issues are valuable assets for service delivery and health promotion for South Asians with Type 2 diabetes.

Involving the ethnic Health Development Workers in education had multiple strengths such as bilingual language skills, a shared cultural background and familiarity with cultural practices, values and belief systems. This would enable the qualified professionals to focus on the more complex aspects of diabetes care rather than be involved in primary care aspects of diabetes management during a consultation with the considerable resource constraints that currently exist for diabetes care.

Education

Implications for education ranged from involving Ethnic Health Development Workers in implementing changes in the curriculum to train professionals involved in diabetic care.

Networking with religious leaders and using the existing informal groups as effective avenues for health education could also probably improve the educational programmes for minority ethnic groups with diabetes. Drop in centres and satellite clinics are the other avenues that need to be explored.

Inclusion of cultural practices by different ethnic groups in the curriculum for training professionals caring for diabetes will be a significant breakthrough in equipping practitioners to provide culturally sensitive care. Provision of services for diabetes involved education on life style changes and practitioners interviewed felt inadequate to educate patients since their knowledge on the socio cultural beliefs and values

influencing health behaviour was very limited. This imposes barriers to their understanding of health practices among different ethnic groups.

Policy

The implications for both practice and education as recommended also have policy implications since it would involve reviewing current policies in terms of resource allocation, distribution and making services available at the Primary care level using the Ethnic Health Development Workers. Despite the recognition in the National Service Framework (NSF) for diabetes in the UK (Great Britain. Department of Health, 2002) that there is a disproportionate increase in the incidence of diabetes among minority ethnic groups, the specific strategies to address this issue among these groups are not clearly outlined. Good risk communication will facilitate the current trend of improving patient's choice and self-management in health care, and there is a need for practitioners to be sensitive to the particular issues faced by South Asians with diabetes care in the UK (Macaden et al., 2006) .

Thus, reviewing the recommendations towards practice and education that have emerged from the data in this study will have implications for policy review in the area of service delivery. Considering the economic burden that long term risks with diabetes would impose, it would be worthwhile to invest in planning strategies to address issues in relation to risk perception and risk communication in the light of the findings from this piece of research.

Critique

The study facilitated an in depth exploration on factors influencing risk perception in diabetes among older South Asians with Type 2 Diabetes and practitioners. However, there was a lack of sufficient representation from within each South Asian community (especially from Bangladesh) to be able to generalise findings specifically pertaining to each group. Difficulties with recruiting South Asians as research participants have been reported by other researchers (McAvoy et al., 1988).

Links were made with the South Asian communities through social networks and community based non religious organisations in an attempt to increase awareness in the community and to maximize the response rate and overcome issues related to the process of recruitment. Gender and ethnically matched ethnic health development workers were also involved in the recruitment of research participants. Despite all this, only one male participant from Bangladesh consented to be interviewed. However, since there was 'data saturation' with interviewing twenty participants, no further attempts were made to recruit. The primary aim of this research was to develop a conceptual model on risk perception among older South Asians in general and not from within each heterogenous group among the South Asians. Therefore, the lack of adequate representation of male participants from Bangladesh has not adversely affected the findings from this research.

A follow up Focus group would have been ideal with the participants (South Asians with Diabetes) to explore specific issues further and this was limited due to the multilingual nature of the participants. Issues in relation to language and the process of interpretation have been dealt with in detail in the chapter on methodology (Chapter 3).

From the methodology perspective, it would have been preferable to have data collected from each participant with more than one interview to explore specific issues in detail with the same participant. With qualitative research emphasizing the celebration of heterogeneity to make the data 'rich' (Robson, 2002b) and the process of theoretical sampling as part of the grounded theory approach used this was overcome. Data was collected from only a single interview with each participant rather than a series of interviews with the same participant which was primarily due to issues with participants consenting to be interviewed more than once. With an upsurge of interest in research among Minority Ethnic Groups, participants expressed not wanting to be interviewed over and over again since they tend to be involved in multiple studies.

Lack of linguistic skills in the researcher was a drawback to be able to conduct the interviews in the source language. The transcripts could not be reinterpreted or verified by language experts due to time and financial constraints. Interpreters had to be depended upon but however, issues related to validity were addressed to the best possible extent as discussed in Chapter 3. The reasons as to why the other interpretive models such as phenomenology and ethnography that were also applicable to this study but not used have also been described in detail in Chapter 3.

Like with any other Qualitative research, the findings cannot be generalised to the entire South Asian community with diabetes in the UK but it certainly does further existing understanding on risk perception among older South Asians with Type 2 Diabetes in the UK. The findings have opened up possibilities for future research and strongly challenge the relevance of the concordance and empowerment model for diabetes care in the UK for minority ethnic groups.

Recommendations for future research

A large scale study to compare risk perception between the Caucasian population and South Asians with diabetes across the UK would facilitate further understanding on the specific differences in risk perception across different ethnic groups. A gender based study to explore gender specific issues in relation to risk perception among the South Asians with diabetes in the UK will enhance our understanding on risk perception in both men and women with diabetes and promote the development and delivery of services accordingly. It would also open up possibilities of addressing gender based issues such as gender hierarchy, empowerment of women, right to information and equal access to services while planning services for the minority ethnic groups living in the UK. A comparative study on risk perception between South Asians with diabetes in the UK and South Asians with diabetes in India, Pakistan or Bangladesh would facilitate understanding of the impact of westernisation or living in a western context on risk perception. The possibility of a similar study on the younger South Asians (second generation immigrants) with Type 2 diabetes will create interesting avenues of exploration on the process of acculturation and the impact of

literacy / fluency with communicating in English and their impact upon risk perception considering the genetic predisposition among South Asians towards developing Type 2 diabetes.

The relevance of the concordance and empowerment model of diabetes care that emphasises self management can be explored across minority ethnic groups with diabetes in the UK.

Conclusion

The influence of cognitive and affective domains in risk perception have been previously documented (Cook, 2006). Both the domains interacting with each other through the dynamics of locus of control resulting in either proactive or reactive risk engagement particularly with diabetes related risks is new knowledge. Risk perception that is inclusive of risk awareness and risk engagement in minority ethnic groups in relation to health related risks has not yet been documented. Thus, the study has made significant contribution to the area of risk in chronic disease among minority ethnic groups.

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APPENDIX 1

PARTICIPANT (OLDER SOUTH ASIANS) INFORMATION SHEET & CONSENT FORM

Study title: Risk Perception among Older South Asians with Type 2 Diabetes in the United Kingdom

Invitation

1st December 2003

You are being invited to take part in a research study to look at **Risk perception among older South Asian men & women with Type 2 Diabetes**. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

What is the purpose of the study?

Diabetes (Type 2) is very common among the South Asian population all over the world and is expected to increase rapidly in the years to come. People with diabetes face problems with their disease which requires many lifestyle changes. It is therefore important to achieve and **maintain a balance between quality of life and adherence to a medical regime**. Type 2 Diabetes could cause many long term complications which are preventable. I would therefore like to identify the varied understanding and management of risks related to Type 2 Diabetes from your cultural perspective.

Who is organising and funding the research?

I am an Associate Professor in Nursing from the Christian Medical College, Vellore, South India and have come on study leave. I am currently a full time Ph. D student under a studentship scheme at the Northumbria University, Newcastle upon Tyne and am conducting this research as part of my PhD.

Why have I been chosen?

You have been chosen because you are from within the South Asian community in Newcastle upon Tyne and your information to the study would be first hand and very valuable.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without

giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect in any way, the standard of health care you receive.

What will happen to me if I take part?

You would be required to participate in a tape recorded interview with the help of an interpreter if necessary. This will take around an hour and a half and the place and time can be arranged according to your convenience. I plan to analyse all these interviews and information and compare those with other participants in the study from the South Asian Community like yourself. Data will be collected over a period of 12 months between February 2004 and February 2005. I plan to complete this study by September 2006.

Sections of your medical notes may be looked at by the researcher where it is relevant to your taking part in the research (e.g.) your blood glucose levels, the current treatment you are on, problems developed related to Diabetes etc. **The official permission to access to your records has been obtained from the Caldecott Guardian which is the regulatory body to give such approval.**

Will my taking part in this study be kept confidential?

All information which is collected about you and from your medical notes during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed one year after the completion of the project. Coding will be used at the time of transcription and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it.

What do I have to do?

Apart from participating in the tape recorded interviews, there is no other requirement. Information from you would be collected in two stages during the interview and this may take between an hour to an hour and a half.

Stage I: The first stage would involve identifying the five most important areas in your life at present.

Stage II: This would involve data gathering through tape recorded interviews. The interview will focus on your experience of living with Type 2 Diabetes in a western cultural setting and your understanding of the risks related to the illness. There would be the availability of the services of a male and female interpreter and you could have the choice of either that are available if necessary.

What are the possible disadvantages and risks of taking part?

There is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this.

What are the possible benefits of taking part?

The information we get from this study may help us to understand the difficulties and issues that you may have in managing your Diabetes or understanding the risks related to Diabetes from your cultural perspective. This would also probably enable us to identify the key factors in designing a culturally sensitive services and risk factor modification which would minimise the long term risks related to diabetes.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, this will not affect your treatment or the services you receive for your Diabetes.

What if something goes wrong?

If you are unhappy about any part of the interview, please contact me or my supervisors (Professor. Charlotte Clarke and Professor. Jan Reed, whose contact details are available at the end of this information sheet) and I will do my best to redress the situation. If you are harmed by taking part in this research project, there are no special compensation arrangements.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at the Northumbria University. Subsequent publication will be subject to procedures in the appropriate journal. The work is published so that a wide range of staff can read it and think about ways of developing Diabetes care. You will not be identified in any report/publication.

Who has reviewed the study?

1. NHS Local Research Ethics Committee.
2. Newcastle Primary Care Trust – Research & Development Department.
3. Northumbria University- School Ethics Sub-Committee.

Contact for Further Information

1. Mrs. Leah Macaden
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3. Professor. Jan Reed
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Please keep this information sheet and a copy of the signed consent form. Thank you for reading this.

**APPENDIX 2
CONSENT FORM – A**

**Title of Project: Risk Perception among Older South Asians with Type 2 Diabetes
in the United Kingdom**

Please initial box

1. I confirm that I have read and understand the information sheet dated 1st December 2003 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by the researcher or regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I understand that information relating to me will be tape recorded during the interview. It will be destroyed one year after the completion of the project.
5. I understand that information relating to me will not be identified by my name, and that this information will be kept in locked storage. It will be destroyed one year after the completion of the project.
6. I agree to take part in the above study.
7. I agree to use the services of an interpreter.
8. I would prefer to use a family member for the interpretation.
9. I agree to inform my GP regarding my participation in the study.

My choice of an interpreter would be Male / Female. (Circle as appropriate)

Name of Participant

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher
Signature

Date

Name of Researcher: Mrs. Leah Macaden, PGR Student (Full time Ph. D Programme), School of Health, Community and Education Studies, Coach Lane Campus, Northumbria University, Newcastle upon Tyne, NE7 7XA.

APPENDIX 3

INFORMATION SHEET FOR HEALTH CARE PROFESSIONALS & CONSENT FORM

Study title: **Risk Perception among Older South Asians with Type 2 Diabetes in the United Kingdom**

Invitation

1st December 2003

You are being invited to take part in a research study to look at **Risk perception among older South Asian men & women with Type 2 Diabetes**. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

What is the purpose of the study?

Diabetes (Type 2) is very common among the South Asian population all over the world and is expected to increase rapidly in the years to come. People with diabetes face problems with their disease which requires many lifestyle changes. It is therefore important to achieve and **maintain a balance between quality of life and adherence to a medical regime**. Type 2 Diabetes could cause many long term complications which are preventable. I would therefore like to identify from your experience the varied understanding and management of risks related to Type 2 Diabetes among South Asian men and women.

Who is organising and funding the research?

I am an Associate Professor in Nursing from the Christian Medical College, Vellore, South India and have come on study leave. I am currently a full time Ph. D student under a studentship scheme at the Northumbria University, Newcastle upon Tyne and am conducting this research as part of my PhD.

Why have I been chosen?

You have been chosen because you are involved in the care of Diabetes of South Asian men and women in Newcastle upon Tyne and your information to the study would be first hand and very valuable.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to

sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

You would be required to participate either in a focus group or an interview. Data gathered will be tape recorded. This will take around an hour and the place and time can be arranged according to your convenience. Data will be collected over a period of 3 months between February 2004 and April 2004. I plan to analyse all these interviews and information. This would add valuable information to the project from your experience, the varied understanding and management of risks related to Type 2 Diabetes among South Asian men and women. I plan to complete this study by September 2006.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed one year after completion of the project. Coding will be used at the time of transcription and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it.

What do I have to do?

Apart from participating in the tape recorded interviews, there is no other requirement. Information from you would be collected during the interview and this may take up to an hour. Data collected would be tape recorded.

What are the possible disadvantages and risks of taking part?

There is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this.

What are the possible benefits of taking part?

The information we get from this study may help us to understand the difficulties and issues that you may have with the South Asian men and women understanding and managing the risks related to Type 2 Diabetes from their cultural perspective. This would also probably enable us to identify the key factors in designing a culturally sensitive services and risk factor modification which would minimise the long term risks related to diabetes.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, this will not affect your treatment or the services you receive for your Diabetes.

What if something goes wrong?

If you are unhappy about any part of the interview, please contact me or my supervisors (Professor. Charlotte Clarke and Professor. Jan Reed, whose contact details are available at the end of this information sheet) and I will do my best to redress the situation. If you are harmed by taking part in this research project, there are no special compensation arrangements.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at the Northumbria University. Subsequent publication will be subject to procedures in the appropriate journal. The work is published so that a wide range of staff can read it and think about ways of developing Diabetes care. You will not be identified in any report/publication.

Who has reviewed the study?

1. NHS Local Research Ethics Committee.
2. Newcastle Primary Care Trust – Research & Development Department.
3. Northumbria University- School Ethics Sub-Committee.

Contact for Further Information

1. Mrs. Leah Macaden
PGR Student (Full time Ph. D Programme)
School of Health, Community and Education Studies
Coach Lane Campus
Northumbria University
Newcastle upon Tyne, NE7 7XA.
Tel: 0191 2362074
E mail: l.macaden@unn.ac.uk
leahmacaden@hotmail.com
2. Professor. Charlotte L. Clarke
Associate Dean (Research)
School of Health, Community and Education Studies
Northumbria University, Newcastle upon Tyne, NE7 7XA.
Tel: 0191 2156090

3. Professor. Jan Reed
School of Health, Community and Education Studies
Northumbria University, Newcastle upon Tyne
NE7 7XA.
Tel: 0191 2156090

Please keep this information sheet and a copy of the signed consent form. Thank you for reading this.

APPENDIX 4

CONSENT FORM – B (For Health Care Professionals)

Title of Project: Risk Perception among Older South Asians with Type 2 Diabetes in the United Kingdom

Please initial box

1. I confirm that I have read and understand the information sheet dated 1st December 2003 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I understand that information relating to me will be tape recorded during the interview. It will be destroyed one year after the completion of the project.
4. I understand that information relating to me will not be identified by my name, and that this information will be kept in locked storage. It will be destroyed one year after the completion of the project.
5. I agree to take part in the above study.

_____ Name of Participant	_____ Date	_____ Signature
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_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
--	---------------	--------------------

_____ Researcher	_____ Date	_____ Signature
---------------------	---------------	--------------------

Name of Researcher: Mrs. Leah Macaden, PGR Student (Full time Ph. D Programme), School of Health, Community and Education Studies, Coach Lane Campus, Northumbria University, Newcastle upon Tyne, NE7 7XA.

APPENDIX 5

Prompt Sheet used for interviews with Health Care Professionals

Introductions

Experience with Diabetes Practice

Experience in the care of South Asians with Type 2 Diabetes

Familiarity with any of the South Asians' health beliefs or cultural practices in relation to health

Experience in dealing with South Asian men with Type 2 Diabetes

Experience in dealing with South Asian women with Type 2 Diabetes

South Asians' understanding of their diabetes

Management of diabetes by South Asians in general

Understanding and management of risks related to their Diabetes

Differences in the way men and women within the South Asian community perceive and respond to risks

Differences between younger & older South Asians with Type 2 Diabetes

Difficulties or barriers faced as professionals in reaching out to their health needs

What changes would you like to see, ten years from now in relation to today's practice / lifestyle among the South Asians with Type 2 Diabetes?

What changes would you like to see within the health care setting in addressing these needs?

APPENDIX 6

Prompt Sheet Used For Interviews with Older South Asian Men & Women

Introductions

Health in general

What was your health like before the onset of Diabetes? How important is your health to you? How important is your health to your family? What were you the most proud of? What did you enjoy the most? What did you not enjoy? How do you normally spend your day?

Understanding and management of diabetes

What went through your mind when you were first told about your Diabetes?

What do you think has caused your diabetes?

What is your understanding of diabetes?

What is it that you find most difficult in living with Diabetes?

How do you manage your Diabetes?

Issues related to Insulin- (Feelings about being on Insulin, Risk of hypoglycaemia, Administration of insulin, Device used, and difficulties with taking insulin)

Issues around medication; Issues around changes in lifestyle practices; Issues around food habits;

Issues around attending hospital appointments;

Would you have managed your diabetes any differently if you were younger?

Impact of diabetes

Has your life changed since the diagnosis?

What are some of the areas of your life that have been affected?

What changes has diabetes meant to you and your family?

Which area of your life has been the most affected as a result of your diabetes?
Have you ever felt you could have done something to prevent this from happening?
Would it have been any different if you stayed in your country of origin? (Impact of migration)
How often do you go back home? Have you been recently? Impact of travel on hospital appointments; Reasons for frequent travel to country of origin;
How do you manage your Diabetes while you are there?
Issues around fasting during Ramadan; Issues around traveling to country of origin; Impact on religious observances; Issues around gender;

Risks around diabetes

What is it that worries you the most about your Diabetes?
Are you aware of some of the risks (complications) that are related to your diabetes?
How did you get to know about them?
How important do you think it is to be aware of the risks involved?
Do you feel you are at the risk of developing complications related to your Diabetes?
If yes, how great is the risk?
Do you feel these risks / complications are preventable?
What do you do to prevent some of these risks / complications?
Does your awareness of the possible risks influence the decisions you make concerning your diabetes?
Has the diagnosis had any positive influence in your life?
Services accessed to prevent / manage risks related to diabetes; expectations from family members / health services to manage risks; issues around smoking & alcohol;

Conclusion

Is there anything that you might not have thought about before that occurred to you during this interview?
Is there anything else you think that I should know about you diabetes?

APPENDIX 7

Data regarding Medical history and Glycaemic Control (from the medical notes)

Participant Number: Age: Sex: BMI:

Marital status: Country of origin:

Occupation: GP's address:

Educational background:

Languages spoken:

Date when Diagnosed:

Date of interview:

Co- morbid conditions (Diabetes related risks):

Smoking: Alcohol consumption:

Access to health services: GP / Diabetes Nurse Specialist / NGH Diabetes Centre

Frequency of visit: monthly / every 3 months / every 6 months / annual / when required

Medical Treatment: Diet Control/ Oral Hypoglycaemic agents / Insulin / Others

Last three readings of HbA1C:

History of hospitalization related to Diabetes:

APPENDIX 8

Date

GP's address

Dear

Risk Perception among Older South Asians with Type 2 Diabetes in the United Kingdom

I am Leah Macaden, a full time PhD student at Northumbria University and have undertaken the above project for my thesis. The proposal has been scrutinised by the School of HCES (Health, Community and Education Studies) Research Ethics Sub Committee and the University Peer Review and was then forwarded to the LREC (Newcastle and North Tyneside) for the Ethics approval. I have obtained the Ethics approval from the Research and Development Unit of the Newcastle Primary Care Trust and the Caldecott Guardian approval to access the medical notes of the participants in the study.

I would like to inform you that Ms. / Mrs. / Mr. ----- from your practice has participated in the study with informed consent. The study involves identifying the various understanding and management of risks related to Type 2 Diabetes among South Asian men and women and does not include any form of evaluation of the service that the participants access. Please do not hesitate to contact me or either of my supervisors as listed below if you need any further information.

- Mrs. Leah Macaden
PGR Student (Full time Ph. D Programme)
School of Health, Community and Education Studies
Coach Lane Campus
Northumbria University

Newcastle upon Tyne, NE7 7XA.

Tel: 0191 2362074

- Professor. Charlotte L. Clarke

Associate Dean (Research)

School of Health, Community and Education Studies

Northumbria University, Newcastle upon Tyne, NE7 7XA.

Tel: 0191 2156090

- Professor. Jan Reed

School of Health, Community and Education Studies

Northumbria University, Newcastle upon Tyne, NE7 7XA.

Tel: 0191 2156090

Best wishes

Yours sincerely

Leah Macaden

APPENDIX 9



Newcastle and North Tyneside Local Research Ethics Committees

Room G14
The Dental School
Framlington Place
Newcastle upon Tyne
NE2 4BW

Tel: 0191 222 3581
Fax: 0191 222 3582
Email: leonard.key@nhs.net

Our ref: PAH/LK/AT/2004/020

Your ref:

22 March 2004

Mrs L Macaden
70 Rayleigh Drive
Wideopen
Newcastle upon Tyne
NE13 6AJ

Dear Mrs Macaden

**Risk Perception Among Older South Asian Men & Women in Newcastle upon Tyne
with Type II Diabetes**

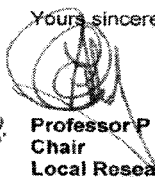
Ref: 2004/020

Thank you for your letter of 2 March 2004 which addresses the issues identified by the Ethics Committee when it considered your application in respect of this study.

In the light of your response I can now confirm the grant of ethical approval in respect of your research study application.

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Yours sincerely


PP. **Professor P A Heasman**
Chair
Local Research Ethics Committee

Enc

Copy to Dr C Mackerness, Research & Development Department, RVI

2004-020 040322

An advisory committee to Northumberland, Tyne and Wear Strategic Health Authority

APPENDIX 10

Newcastle 
Primary Care Trust

RESEARCH AND DEVELOPMENT DEPT
Newcastle Primary Care Trust
Benfield Road
Newcastle upon Tyne
NE6 4PF
Tel: 0191 219 6067
Fax: 0191 219 6105

Project ref: 2004DIAB002

4 February 2004

Mrs Leah Macaden
Post Graduate Research Student
School of Health, Community and Education Studies,
Northumbria University
Coach Lane Campus
Newcastle upon Tyne.

Dear Leah

**Re: Risk perception among older South Asian men and women
in Newcastle upon Tyne with Type II Diabetes.**

Thank you for sending me information about the above project. I am pleased to inform you that the Trust supports your proposed research study and is happy for you to carry out the work on Trust premises and use Trust patients.

We have registered your project on the Trust Research and Development Database and will keep in touch with you on a regular basis to update our records on your progress. Should you make any changes to your research study you should inform the R&D office at the address above as soon as possible.

Your attention is drawn to your requirement as lead investigator to ensure that the research complies with the Data Protection Act and Health and Safety legislation. We advise that you read the Research Governance Frame work for Health and Social Care



Gina Tiller - Chair

Headquarters: Benfield Road, Newcastle upon Tyne, NE6 4PF

(www.doh.gov/research/rd3/nhsrandd/researchgovernance.htm),
particularly the sections 'responsibilities of researchers' and
'responsibilities of the principal investigator'.

We will also need a copy of your ethics approval letter when you receive it. This document enables the Trust to comply with Department of Health criteria for research governance.

For your information:

The Trust has to audit a sample of projects part way through the project to ensure compliance with Research Governance Regulations. You will be contacted by the R & D office if you are required to do this.

Please do not hesitate to contact us if you require further assistance

Yours sincerely



Debbie Freake (Dr)
Medical Director



Liz Hanley
Research and Development Manager

APPENDIX 11

Newcastle 
Primary Care Trust

Vida Morris
Director of Nursing &
Clinical Services
Benfield Road
Newcastle upon Tyne
NE6 4PF

Tel: (0191) 2196049
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/M/SJ

18 December 2003

Leah Macaden
Post Graduate Research Student
Diabetes Centre
NGH H07

Dear Leah

**RE: RISK PERCEPTION AND MANAGEMENT OF RISK
AMONG SOUTH ASIAN MEN AND WOMEN WITH
TYPE II DIABETES**

Thank you for forwarding a request for Caldicott Approval in relation to the above study, I enclose the form of approval for your records.

As Caldicott Guardian for Newcastle PCT I am happy to give approval, however would be most grateful if you could forward a copy of ethical approval once received.

May I wish you success in taking this work forward,

Yours sincerely

Vida Morris

Vida Morris
Director of Nursing & Clinical Services

cc Dr Gillian Hawthorne, Consultant Community Diabetologist
Anne Robinson, Diabetes Centre Manager



Gina Tiller - Chair

APPENDIX 12

**Risk perception among older South
Asian people in the UK with
Type 2 diabetes
(Published Paper)**

Risk perception among older South Asian people in the UK with type 2 diabetes

Leah Macaden MSc (N), RN, RM

Professor in Medical and Surgical Nursing, College of Nursing, Christian Medical College, Vellore, India, and PhD student, Northumbria University, Newcastle upon Tyne, UK

Charlotte L. Clarke BA, MSc, PhD, PGCE, RN

Professor and Associate Dean (Research), Community, Health and Education Studies Research Centre, Northumbria University, Newcastle upon Tyne, UK

Submitted for publication: 25 April 2006

Accepted for publication: 10 May 2006

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MACADEN L. & CLARKE C. L. (2006) *International Journal of Older People Nursing* 1, 177–181

Risk perception among older South Asian people in the UK with type 2 diabetes

Aim. To report on a study which developed a knowledge of the experiences of South Asian people with diabetes in the UK in relation to socio-cultural and dietary practices, religion and ageing influences on the perception and understanding of risks.

Background. South Asian people have enhanced vulnerability to poor health as a result of diabetes. Risk perception and management is culturally mediated, yet imperative to the behaviour adjustments required for diabetes management.

Method. A grounded theory study with data collected by focus group with ethnic health development workers and individual interviews with 20 older people with diabetes. Where necessary, interpreters were involved in data collection.

Findings. A number of issues influence the perception of risk among South Asian older people with diabetes: beliefs about its cause, perceived severity and its visibility, food and its social function, religion and beliefs about external control over their life span and diabetes management. People weighed up the risks in making decisions about issues such as dietary management and the emphasis placed on diabetes as a pathology.

Conclusion. Good risk communication will maintain the current trend of improving patient's choice and self-management in health care, and there is a need for this to be sensitive to the particular issues faced by South Asians with diabetes in the UK.

Key words: culture, diabetes, religion, risk, South Asian

Introduction

Rapid population ageing because of improved life expectancies and decreased fertility rates worldwide poses immense challenges to health and social services. With the increasing proportion of older people, the incidence of people developing non-communicable diseases (NCDs) and the associated disability will also escalate. NCDs including cardiovascular

diseases, diabetes and cancer are predicted to be the main contributors to the burden of disease in developing countries by 2020 (Murray & Lopez, 1996) and will be responsible for over three-quarters of all deaths. Diabetes mellitus (DM) has become a seriously threatening global health problem, and is reaching epidemic proportions worldwide with serious implications for morbidity and mortality (Zimmet *et al.*, 2001). The pandemic involves essentially non-insulin-dependent

diabetes mellitus (type 2 DM), which comprises about 85% of all DM cases (Zimmet *et al.*, 1997).

The prevalence of type 2 diabetes has been escalating among South Asian people in many parts of the world including the UK (Riste *et al.*, 2001) and is more than twice as high in South Asian people than Caucasian counterparts (Abate & Chandalia, 2001). South Asian people have the highest death rates from coronary heart disease in the UK (Balarajan, 1996), with Bangladeshis being particularly disadvantaged (Bhopal *et al.*, 1999). Many of the risk factors for these complications such as poor glycaemic control, smoking, elevated blood pressure and dyslipidaemia are modifiable and early interventions are therefore important in South Asian people with type 2 diabetes (Chowdhury & Lasker, 2002).

Risk perception

Risk perception has been defined as 'involving people's beliefs, attitudes, judgements and feelings as well as the wider cultural and social dispositions they adopt towards hazards and their benefits' (Pidgeon *et al.*, 1992). It has different meanings to different groups of people and all risks need to be understood within the larger social, cultural and economic context (Gifford, 1986; NRC, 1996), these influencing individual perception of risks and autonomy to manage risks (Douglas & Wildavsky, 1982). Therefore, risks should not be treated independently and separately from the complex social, cultural, economic and political circumstances in which people experience them (Nelkin, 1989; Ogden, 1995).

Risk perception is multidimensional, with a cognitive dimension (how individuals assess their own likelihood of coming to harm) and affective dimension (the uncertainty, concern, worry or anxiety that people feel about potential harm) (Park *et al.*, 2001). Generally, people tend to underestimate risks associated with voluntary behaviours of their choice as against risks that are likely to be present from external sources. The magnitude of risk perceived by the individual depends upon whether the risk is perceived to be voluntary (Lima *et al.*, 2005), familiar, less visible (Barnett & Breakwell, 2001), amenable to treatment (Adams & Smith, 2001) or associated with obvious benefits and impacts. Changes in health risk perceptions may or may not facilitate positive health behaviours. However, understanding the socio-cultural factors that impact on health risk perception is necessary for designing mitigation, health promotion and disease prevention strategies (Tate *et al.*, 2003). For people with type 2 diabetes risk perceptions are likely to be influenced in particular by the lack of immediate visibility of associated risks and by feelings of lack of control over prevention.

Diabetes management requires behaviour changes which are dependent upon risk perception. However, individuals who have grown up in a society based on 'dependent collectivism' with hierarchical relationships and class differences learn to obey authorities, which leads to less independent behaviour, infrequent independent thinking, lowered self-efficacy and higher reliance on others (Oettingen, 1995). Hjelm *et al.* (1998) report that South Asian people tend to perceive that somebody else (mainly the physician) takes control of their disease and in their minds they transfer the responsibility of managing their disease to the healthcare professional. Negative outcomes of any sort are often attributed to fate and an acceptance of powerlessness over the situation (Crisp & Barber, 1995).

The South Asian culture

South Asian people (a term used here to refer to migrants to the UK from Bangladesh, India and Pakistan) (Bhopal *et al.*, 1999) comprise approximately 3% of the UK population (Census, 2001). The South Asian population is heterogeneous (Bhopal *et al.*, 1999) with significant language, religious, social and cultural differences not only between South Asian people and European people (Hawthorne *et al.*, 1993) but also between different groups of South Asian people. Key areas in which these differences manifest of relevance to diabetes management are:

- **Dietary practices.** These vary between religious beliefs and country of origin. The fat ghee provides a 'richer' taste to food and is used in several ceremonies because of its religious symbolism (Hawthorne *et al.*, 1993). A larger body size is perceived as an indicator of better health (Greenhalgh *et al.*, 1998) and as a sign of affluence. Hospitality is greatly valued, with sweets, deep-fried snacks and sugared coffee or tea offered as a welcoming gesture. The importance of social etiquette makes it impolite to refuse such a gesture and people with diabetes often find it difficult to mention their dietary restrictions to their hosts.
- **Religion.** The religious groups among the South Asian people consist primarily of Hindus, Sikhs and Muslims. Religion does not seem to have a major influence on the diabetic control among the Hindus and Sikhs unlike among the Muslims for whom going on a pilgrimage to Mecca (Hajj) and fasting during Ramadan are religious duties with a very high priority and visiting the mosque to pray on Fridays are essential features of religious duty (Hawthorne *et al.*, 1993).
- **Health.** Health beliefs and healthcare philosophies between South Asian and European populations are very different (Helman, 2000), e.g. health issues are the concern of the

family rather than the individual (Fuller, 1995; Husband, 1995).

- *Ageing.* Perceptions of ageing vary and are influenced by cultural differences across an individual's life span including the timing of major life events such as marriage, childbirth, familial responsibilities and arrival of grand children. Ethnic life course inequalities are magnified as an individual ages, as is the consequent disempowerment.

Effective management of diabetes involves prevention of long-term risks which requires lifestyle modifications; and therefore, the study reported here aimed to develop a knowledge of the socio-cultural and dietary practices, religion and ageing that influence the perception and understanding of these risks.

Study design

A grounded theory methodology was used and ethical and governance approval was secured from the appropriate organizations. Data was collected by focus group interviews with ethnic health development workers and seven individual interviews with healthcare professionals and 20 South Asian men and women with type 2 diabetes who are living in NE England. Representations were sought from non-English speaking groups (comprising eight of those interviewed) and the Bangladeshi community (five of those interviewed). Interviews with those who were non-English speaking was done using the ethnic health development workers as interpreters and the Cross Language interpretation process (Larson, 1998).

All the interviews were digitally recorded and transcribed, and returned to the respondent for validation wherever possible. Issues related to validity and rigour were addressed using triangulation at two levels (data and interdisciplinary) (Robson, 2002), reflexivity (Ahern, 1999), peer debriefing and maintaining an audit trail (Cutcliffe & McKenna, 2004). Data is being analysed using NVIVO 2, a Qualitative software package, and this paper reports some of the initial open coding (Robson, 2002).

Findings

Factors influencing risk perception

Those interviewed attributed their diabetes to a range of issues such as the cold weather in the UK and having eaten too many sweets in the past. The daughter of one woman with diabetes (F11) stated that 'she believes that she has got the diabetes from worrying too much. She was mourning the loss of her brother in Pakistan, who died very young when

she was first diagnosed'. Others attributed their diabetes to a spiritual fate, as in the following quote.

Actually we don't believe in these things. You know, how in this country they do believe like I should have been in good diet from childhood then I might not be getting it. We don't believe in that. Our fate is totally different. It's like you think, Allah decided to give you the illness, He will. No matter how well you are or how healthy you are. (Interpreter of F3)

The severity of their diabetes was perceived to depend on whether they are on insulin or not, the number of tablets they take and the frequency of hospital visits that they made. The invisibility of the consequences of poor management was something that the health professionals addressed as being an important factor influencing perception and understanding of long-term risks, as illustrated in the following quote from a focus group with the ethnic health development workers: 'you can't see how that's affecting everything...how it's going to be have long term complications... I don't think a lot of people see that' (Health Development Worker – Focus group).

The importance of food and the family dynamics involved seem to influence the dietary practices that need to be modified while caring for one's diabetes especially when the individual affected is the woman.

One lady

South Asian said 'I cannot make, use oil because my husband, he doesn't like ummm... He says meal is not tasty, this and that. I have to make everything in ghee'. Not all families, in fact it's going lesser and lesser now that people are getting the message of using oil, healthy food but there are still few families. (Health Development Worker – Focus group)

The people with diabetes interviewed, irrespective of their gender, expressed the view that the control of their diabetes management was mostly external to themselves and was the responsibility of healthcare professionals and medication. In the following quote one of the health development workers describes how extensive the support needs to be.

I've been off three weeks, I realised that one of the ladies had a Diabetic centre appointment. So, I rang her to see if she went. She goes, 'No, I didn't go. Why didn't you remind us?' I think, Ah! I've been reminding her for the past four, five years and for once I was off sick and I couldn't remind her. So, she didn't go. So, you know, just to take it like responsibility, know how serious it is that you have to attend your Diabetic appointment, not just to wait for somebody to remind you all the time. (Health Development Worker 3 – Focus group)

This passivity about self-management extended to people's perceptions of ageing, with an emphasis again on the

predetermined nature of this: 'So, overall, people put a lot of things down to fate anyway especially when it comes to age, how long you're going to live. And if you've lived a fairly reasonable life, you know you don't bother, you don't take that much of a consideration, really' (man with diabetes, M1).

The predetermination of people's lives was attributed to their religion, and this played a very major role in the perception of risk among the South Asian Muslims in particular, as described in the following quote.

Being Muslim you know, we believe that the time of your death has been recorded before you come into this world in the womb of your mother you know, after the thirteenth day of conception. Nobody can change it you know. But nevertheless, it doesn't, the faith doesn't say, 'You indulge in stupid things and you kill yourself'. You take all the precautions you know, whatever are available and then leave it to God you know. So, I think nobody can do anything about what time has been fixed. Nobody can bring it forwards and nobody can postpone it, you know. (Man with diabetes, M8)

Fasting during Ramadan, going on 'Hajj' and attending prayers regularly were given a very high priority, especially among men. There were instances of people fasting at whatever cost which involved taking insulin and adjusting their meal timings accordingly as their religion requires them to do so and there were other instances where women especially chose not to fast on health grounds as there were other forms of dispensation that could be made instead, as described in the following quote.

I pray and do other things you know, but fasting, I don't do fasting but I know that because of my illness and our religion allows it if you are ill, you don't have to fast but lots of people I know in the community, they have diabetes but they are still fasting. (woman with diabetes, F10)

Weighing up risks

There were several situations described by the participants which required a decision to be made based on weighing up different risks. This often happened in relation to eating practices, where the risk of causing social offence had to be considered alongside the risk of less than ideal diabetes management. In both of the quotes below, the participant describes how the diabetes affects the individual's ability to socialize.

When she goes to somebody's house you know, she cannot say that 'I'm hungry. I need to eat', because she is on Insulin and she has to see to the time of her meals. Same thing with the parties, she has to avoid the parties because of this. (Woman with diabetes, F6)

Any social ceremony or if you go to visit somebody, you will carry one or two kilos of sweets with you, you know. If you take healthy food like fruit, etc., they will look down on you that: 'They have insulted us and brought fruits to our house when they came'. It's that sort of perception. (Man with diabetes, M8)

In another instance, a man with diabetes described how he sought to de-pathologize his diabetes to maintain his familiar life.

No. I'm not looking at it as an illness. If you think too much about the illness, then I become hell, you see. You cannot survive you see. You have to live with peace of mind as you have no illness or nothing like that. I try to have normal life. (Man with diabetes, M4)

Discussion

The current emphasis in health care is on evidence-based practice (Department of Health, 1996) which requires the use of technical evidence. There is interplay between lay and scientific knowledge especially in chronic diseases where health promotion is an integral component in disease prevention and management. This has propagated interest in accessing lay views with health-related issues and also in particularly understanding how meaning is attributed and practised within the relevant socio cultural context (Milburn *et al.*, 2000).

The current study has thrown significant light on how risk perception in older South Asian people is influenced primarily by their understanding of the disease, perceptions of its severity, ageing, dietary practices and religion. They appear to manage these risks either through minimizing the presence of diabetes or by weighing up the consequences of actions that they need to take and balancing these risks.

Lack of knowledge about any culture can predispose to generalization and stereotyping. The 'language of risk' is not the same between patients and practitioners. Good risk communication will facilitate the possibility of making 'informed choices' and maintain the current trend of improving patient's choice and self-management in health-care (Walter & Britten, 2002).

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APPENDIX 13

**Variations in risk perception: South
Asians living in the UK and their
Health care professionals
(Published Paper)**

Variations in risk perception: South Asians living in the UK and their healthcare professionals

Leah Macaden

Diabetes has become a global health problem, reaching epidemic proportions worldwide with serious implications for health and well-being. The International Diabetes Federation estimates that by 2025, almost 350 million people will have diabetes. People who are most vulnerable to this chronic disease include those living in developing countries, and members of minority ethnic groups and socio-economically disadvantaged people in developed countries. Leah Macaden reports on a study which looked at the differences in the way the risks from diabetes are perceived by people of South Asian origin living in the UK and their healthcare professionals.

South Asians (migrants from Bangladesh, India and Pakistan) comprise approximately 3% of the population of the UK.¹ The South Asian population is heterogeneous and has marked language, religious, social and cultural differences. South Asians in general have an increased vulnerability to developing type 2 diabetes when compared to Caucasians.² This is believed to be due to an excess of insensitivity to insulin, determined by environmental and/or genetic factors.³

What is risk?

Science and medicine understand and define risk quite differently compared to people without a medical or scientific background. While the scientific community view risk as an objective reality that can be measured, controlled, and managed, it is often socially constructed, and in general is understood differently by different groups of people depending on their socio-cultural context. Perceptions of



Perceptions of the risks associated with type 2 diabetes are shaped by cultural influences.

risk and its significance to individuals can vary between developing and developed countries, and involve such variables as age, gender, faith and cultural groups, urban versus rural settings, and geographical location.

Chronic conditions often involve physical or mental impairment.

Demands, disruption and uncertainty

Chronic conditions often involve physical or mental impairment and demand that daily living is designed around the management of symptoms. Chronic conditions also represent a loss of integrity – the wholeness of the individual when any part of the body does not function properly. They tend to disrupt daily routine and structures – the features that are usually taken for granted, and the practical knowledge on which the individual's experiences are based.⁴

Any chronic condition imposes practical consequences for people and their families. Demands are placed on time for the management of symptoms and medical treatment; disruption is provoked at home and in the workplace; and there are socio-economic implications for long-term management. Moreover, chronic conditions, such as diabetes, are associated with many uncertainties – for example in terms of diagnosis and symptoms.

Effective diabetes management involves several elaborate rituals, such as blood glucose monitoring, daily exercise, weight reduction and diet restriction, which provoke minimally noticeable change to the person with the condition.

Barriers to adherence

A number of concomitant factors make adherence to treatment difficult, including the complexity of the treatment and lifestyle changes that are required, barriers to access-

ing services, an unsupportive social environment, and the extent to which a person's everyday life is affected. Although healthcare professionals often have difficulty in understanding non-adherence to treatment among people with diabetes, there is often a rational basis for non-adherence from the patient's point of view. For instance, quite often, people with type 2 diabetes do not feel noticeably unwell – except for generalized weakness and fatigue – even at diagnosis.

When people start taking a blood glucose-lowering drug, such as metformin, they are likely to develop side effects, including gastro-intestinal disturbances such as diarrhoea, and subsequently feel quite unwell. Understandably, these people often associate the drug with contributing to their lack of wellness and it is not uncommon for them to discontinue it.

People often associate a drug with their lack of wellness and discontinue it.

Risk perception in the UK

A recent study compared the risk perceptions of South Asian adults with type 2 diabetes who live in the North East of England with those of healthcare professionals working in the same area.

Data were collected through group sessions with ethnic health-development workers, individual interviews with healthcare professionals (physicians, nurse specialists and a dietitian), and interviews with South Asian men and women with type 2 diabetes. Both non-English-speaking and English-speaking South Asians were involved in the study, representing the three major South Asian communities in the UK – Bangladeshi, Indian and Pakistani.

Findings

It was found that a number of issues influence the perception of risk among older South Asian people with diabetes: views on ageing, family dynamics, culture, the significance of food (especially in terms of hospitality), beliefs about the causes of diabetes, its perceived severity and visibility, the lack of visibility of proposed risks, religion, and beliefs about external control over lifespan.

It was interesting to note that there were very specific variations in the way risks that are related to type 2 diabetes were perceived by people with diabetes and the healthcare professionals working with them. Some of these are outlined below.

Cause

While healthcare professionals involved in diabetes care pointed to a lack of insulin and the subsequent metabolic changes as the causes of diabetes, the people with the condition believed that fate and the cold weather and lack of sunshine in the UK were to blame, together with a familial predisposition, having eaten too many sweets in the past, excessive worries or having experienced a stressful situation.

Management

For the healthcare professionals, the key to good diabetes management lies in nutritional control, weight reduction if necessary, regular exercise, monitoring of blood glucose levels, regular medication, and follow up. While the South Asians with type 2 diabetes concurred with the healthcare professionals in terms of the need to avoid consuming excess sugar and avoid fried food, there was little mention of weight reduction and exercise.

Perception of severity of diabetes

Among the respondents with diabetes, the number of tablets taken and services accessed were among the key factors defining the severity of a person's condition (people who accessed the diabetes centre were perceived to have a 'more serious form of diabetes' than people who only visited their family doctor for their diabetes management). The frequency of hospital appointments and whether or not insulin was prescribed were also factors.

There was very low awareness of the possible long-term complications of diabetes.

Risks related to diabetes

Worryingly, there was very low awareness of the possible long-term complications of diabetes – hypertension, heart disease, stroke, blindness and kidney failure – and ways to prevent them. Risks were weighed up in terms of interference

with social and religious requirements, such as the inability to attend social gatherings due to dietary constraints; the inability to fast and practise religious observances; and social offences such as turning down food (particularly sweets), which are offered as a sign of hospitality while visiting friends and family.

People believe that doctors, medications, luck and God will 'look after' their diabetes.

Locus of control

While the healthcare professionals emphasized self-management and the need for individuals to take responsibility for their diabetes management, the respondents indicated external factors: that their doctors, the medications, fate, luck and God would 'look after' their diabetes.

Barriers

Interestingly, a number of healthcare professionals highlighted their own lack of understanding of South Asian culture. The people with diabetes lamented the lack of South Asian professionals within the diabetes services – to discuss their dietary concerns in particular. There was also a perception that resources were not equally distributed for access to diabetes care.

Some healthcare professionals highlighted their lack of understanding of South Asian culture.

Conclusion

There is interplay between medical and non-medical knowledge of risks, especially in chronic diseases, where health promotion is an integral component in preventing or managing those risks.

For people of South Asian origin, perceptions of the risks associated with type 2 diabetes are shaped by a range of different factors, including cultural influences on gender roles, family life, and the significance of food and its preparation.

The healthcare providers' perceptions of the risks associated with diabetes are influenced by their technical, rational ap-

proach, and a purely medical model of risk-management that assumes a 'Western' approach to food and family.

This study partly addressed the need for 'sensitive exploration of the ways in which policy-makers, practitioners and service users understand and manage risks in specific healthcare contexts'.⁵ While it is hoped that the findings will inform practitioners of the need for planning and developing culturally sensitive services to South Asian people with type 2 diabetes living in the UK, the wider significance for migrant communities living in other countries should also be noted.

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