

**SOCIAL POLICY AND HEALTH INEQUALITIES:
the relevance of faith to chronic illness
management in the Pakistani community**

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ABSTRACT

Two historical frameworks dominate European discourse about Muslim identity. First, the Enlightenment notion that religion is a private matter to be disassociated from public life, particularly from the scientific enterprise. Secondly, the Orientalist tradition of portraying Islam as inferior to Western culture and Muslims as people to be feared and controlled. These discursive practices have consequences for the everyday lives of Pakistani Muslims in the UK and for their healthcare and health.

This thesis aims to assess the influence of Muslim identity on healthcare and health through a multifaceted methodology, which takes account of context and of other aspects of identity such as social class, ethnicity, gender and age. Findings show that dominant conceptualisations of Islam and Muslims corrupt the communication process between Pakistani people and health practitioners and expose Pakistani people to stereotypical ideas about their beliefs and practices. Furthermore, discussion of religious influences on self-care is avoided by patients and practitioners alike. Consequently, Pakistani people receive inadequate support in decision-making about chronic illness management and are more likely to develop complications. This disadvantage is exacerbated by ethnicity and gender.

These dynamics of healthcare reflect discrimination that is mirrored in almost all contexts in the wider UK society, affecting education, employment and civic participation. These areas affect health status, as does self-perception of social position and social relations. The disadvantage to which Muslim identity appears to expose individuals and groups suggests a possible explanation for higher levels of mortality and morbidity within this community compared to other minority ethnic communities.

This thesis explores the implications of these findings for practice, policy, research and activism. It concludes that developing shared understanding and common ground needs to be a focus for policy and practice development. Policy support for Muslims to organise on the basis of faith identity is also needed if health inequalities within the Pakistani Muslim community are to be effectively addressed.

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INTRODUCTION

Chronic illness and inequalities in health have been a particular focus of health policy in recent years. National service frameworks for conditions such as diabetes and coronary heart disease have aimed to introduce consistency in national standards for treatment. They have also highlighted the importance of partnerships and effective communication between professionals, patients and carers and between different service providers (Department of Health 2001b; 2002)

Compared with the white population, Type 2 diabetes is up to six times more common in Pakistani people. The risk of death from diabetes is between three and six times higher, with this group also being particularly susceptible to the cardiovascular and renal complications of diabetes. Death rates from heart disease are also two to three times higher in this group (Acheson 1998). Inequalities in the health of different ethnic groups have been further highlighted in cross-Government reviews of policy (Department of Health/HM Treasury 2002). These inequalities are acknowledged as arising from a range of causes. At a strategic level, the need to address social issues such as exclusion, stress, crime and poverty in attempts to improve health outcomes is balanced against the need to promote individual responsibility for health (Department of Health 2000).

Various initiatives to address health inequalities have been put in place both nationally and at a local level. Service providers are urged to identify unmet need and to ensure that services are appropriate to address areas such as language, culture, religion, gender and age. The designation of some geographical regions as Health Action Zones has attempted to encourage innovative local projects and to make use of the learning and expertise developed within local communities and the voluntary sector (Bauld and Judge 2002). Health improvement activities targeting chronic conditions are a vital element in the implementation of the White Paper, 'Our Healthier Nation' (Department of Health 1999). The stated aim of key interventions is to ensure that prevention and treatment services:

'reach those in greatest need or with poorest health outcomes, including disadvantaged groups and ethnic groups with high prevalence.'

The responsibility of delivering these programmes to improve local health outcomes has been largely entrusted to the newly established Primary Care Trusts. The White Paper envisages PCTs forging partnerships between organisations and encourages the use of

existing structures, such as Local Strategic Partnerships, for joint work between PCTs and local authorities, along with other local partners and community organisations. The importance of this kind of work is particularly highlighted in relation to disadvantaged groups and areas. A strong emphasis on partnerships between statutory and voluntary sectors aims to achieve long-term, sustainable developments in mainstream services and to target benefits towards those suffering material disadvantage or who have traditionally been poorly served.

Such focus on inequalities has been long called-for in the literature on ethnicity and health. A strong policy lead has been recommended in various studies highlighting higher prevalence, poor access and inappropriate services for minority ethnic communities (Modood et al 1997; Nazroo 1997). How this lead is followed in practice is the focus of this thesis, which explores and evaluates the wide range of contexts and relationships in which Pakistani people communicate and make decisions about how to manage chronic illness. The study aims to support the development of policy and practice, based on well contextualised knowledge, to aid improvements in health and health care.

Chronic illness is, by definition, long term and the biophysical changes involved can have a profound impact upon the daily lives of individuals and those who care for them, their social relationships and their identity. The experience of such illness has therefore been a focus of sociology. Studies have shown that responses to chronic illness are shaped by the social, cultural and ideological context of a person's biography (Nettleton 1995)

The literature suggests that, as a framework for understanding the experiences of Pakistani people, ethnicity does not provide a complete picture and the distinct influence of religious identity needs to be acknowledged. Research amongst South Asian communities has shown multiple identity claims in operation (Modood et al 1997; Ahmad et al 2002). These differ between geographical and social groups; however, there is evidence that religion is of prime importance in the self-description of Pakistani and Bangladeshi people, with little variation in relation to age, gender and class (Modood et al 1997; Birke and Whitworth 1998). In other South Asian groups religious identity is also very important, coming a close second to ethnicity for Indian and African Asian people (Modood et al 1997). Despite these findings, this aspect of identity has received little or no attention in studies of health and social care amongst these communities. Ethnicity, on the other hand, has been adopted as the theoretical framework of a considerable number of such studies.

The following research questions are explored as a means of assessing the influence of religious identity on chronic illness management and assessing how well current policy and practice approaches meet the needs of people in Pakistani Muslim¹ communities:

- How does communication between different stakeholders affect chronic illness management and what is the influence of religious identity on this process?
- What are the different factors that affect patient² decision-making in relation to their health and how influential are religious beliefs?
- What impact does Muslim identity have on the lives of Pakistani people and what does this tell us about inequalities in healthcare and inequalities in health?

I particularly focus on communication and decision-making because expectations and assumptions rooted in values and beliefs play an important role in both these processes (Lago and Thompson 1996). They consequently provide a rich source of data to explore the impact of religious beliefs. Exploration of communication and decision-making has been shown to reveal other influences related to age, gender, social class and the illness experience itself (Charmez and Olsen 1997). My approach avoids the danger of essentialising religion by taking account of these other aspects of identity, which may also affect the experience of Pakistani people with chronic illness. Through an exploration of concrete and specific experiences, the research aims to highlight not only shared belief frameworks but also the diversity that may exist within and between different respondent groups.

This thesis is presented in four parts. The various sections of Part I, the literature review, provide the context in which this study took place. The review explores the way religion has been conceptualised both within existing studies of health and social care and in relevant social policy. Beginning with a historical exploration of how religion has come to be understood in healthcare research and practice, the review goes on to examine the relationship between ethnicity and religion and offers reasons for the dominance of ethnicity as a framework for social policy. An analysis of social policy documents enables deconstruction of current thinking in relation to ethnicity and religious identity. This is

¹ The sample of 'Pakistani Muslims' included people who self-identified as Muslims and were either born in Pakistan or used the community networks of the majority Pakistani population (see Chapter 8 'Community Diversity' for further discussion of 'the Pakistani community').

² This term is used to differentiate people in different respondent groups, whilst recognising that people with chronic illness are 'patients' for very little of their time.

essential because the way these concepts are interpreted is likely to inform professional culture and influence how health professionals work and are trained. Professional understandings of religion and ethnicity can then usefully be compared with the lived experience of people within the Pakistani community.

To assist this comparison I have used a model for understanding how faith operates within the Pakistani community. The model, which considers the influence of religion at an individual, family and community level, corresponds to the methodology for this research and is a useful way of breaking down the complex dynamics involved. This is likely to be useful to professionals, who may feel disempowered by their ignorance of these dynamics and of the beliefs that drive them. Members of Pakistani communities are also likely to find this model useful as they are faced with conflicting experiences of their faith in different contexts: discrimination and exclusion exist alongside the experience of faith as a powerful personal resource and a mobilising force within the community. Understanding how religious identity influences interaction in all these contexts can help to develop a deeper understanding of this aspect of identity and its significance for the health and wellbeing of Pakistani Muslims.

As further background to this study, demographic data from the most recent Census figures provides additional information about the Pakistani population as a social group. National and local data is used to explore the relationship between religious identity and disadvantage. Analysis of this data suggests that religion offers an additional form of identification that can increase our understanding of how discrimination is experienced by Pakistani individuals and communities.

Part II of the thesis details the methods used to explore the research questions. Research into the health experience of people from minority ethnic communities has traditionally developed a snapshot picture from interviews with service users, sometimes alongside those of carers and healthcare professionals (see, for example, studies in Ahmad 2000). This study places these accounts in context by examining the different settings in which healthcare takes place. An ethnographic approach is used to explore the individual experience of people with chronic illness and the accounts of others involved in their healthcare. These individual experiences are set alongside observations of family, clinical and community settings as well as data relating to the wider context of UK society. This approach fits well with current policy positions, outlined earlier, which take account of the

wider determinants of health and which promote interventions at both personal and social levels to improve health outcomes.

The findings, in Part III, illustrate in detail how Pakistani people with a chronic illness learn to live with and manage their condition following diagnosis and the effect on this process of interactions with others in family, healthcare and community settings. Additionally, they show how much impact interventions to address inequalities currently have on the lives of people from this social group. Findings related to communication and decision-making are of particular value for issues such as concordance and for developing effective protocols to help Pakistani people with chronic illness manage self-care regimes. In relation to my third research question, findings suggest that Muslim identity exposes Pakistani people with chronic illness to discrimination in a wide range of settings. This leads to inequalities in healthcare that reflect inequalities in the wider context of UK society.

The final part of the thesis brings together findings from these individual and social contexts and discusses their implications for policy and practice as well as for research and activism. Specific ways in which practitioners can act upon the findings to improve their cultural competence are suggested. In addition, the need for strategies that address the inequalities faced by Pakistani people in a range of contexts, including but extending beyond healthcare, is emphasised. Findings about religious identity are used to suggest reasons why the incidence of morbidity and mortality in the Pakistani community is higher than in the general population or, indeed, in many other minority ethnic communities.

This final chapter also demonstrates the importance of an evidence base which establishes both that a response to religious discrimination is needed in health policy and that interventions are feasible. The policy process is ultimately a political one in which congruent values must be sought and negotiated and in which bargaining and compromise between different interest groups and power bases take place (Exworthy et al 2003). The findings of this thesis are used to highlight opportunities and barriers in this process and to suggest ways forward in the effort to overcome inequalities in health.

PART I: REVIEW OF LITERATURE

Introduction

This review of literature was significant at various points in the study and the context it provided helped to inform the research process. Initially, the review offered a number of themes that contributed to the framework within which semi-structured interviews with respondents were conducted. During fieldwork, new themes arose which were then explored within policy and existing literature. At the stage of analysis, knowledge of existing studies also helped in the development of explanatory models that accounted for empirical observations (Mason 1996). The review thus provides a background in which to understand the findings of this research and offers a framework for later discussion of these findings.

The literature review was conducted through keyword searches in Medline, Psychlit and Sociological Abstracts. Social policy documents were accessed via keyword searches on the Department of Health, Home Office and other relevant websites. Similar use of keywords in the Leeds University library catalogue highlighted books and chapters in addition to journal articles. Contact with others working in related fields was also helpful in terms of identifying relevant literature and policy documents. For example, my membership of e-lists relating to ethnographic research, health inequalities, ethnicity and Muslim groups provided up-to-date information on emerging literature and policy and on useful websites. Attendance at a number of seminars and conferences during the course of the study and discussions with colleagues at such events was also helpful in this respect.

The following four chapters explore the influence of faith on health both within faith communities generally and within the Pakistani community in particular. As already highlighted in the introduction to this thesis, health and social care research in this community has traditionally focused on ethnicity and this has often blurred the significance of faith as an aspect of individual and group identity. The review considers the relationship between these two aspects of identity and the implications of this relationship for understanding both concepts. A correct understanding of the interaction between them is vital in relation to the Pakistani community and perhaps to all ethnic communities.

The review suggests that religious and ethnic identities can overlap but cannot replace each other. As a way of defining social groups, each concept may at times be more appropriate

than the other and the way these identities interact can help to explain complex dynamics relating to communication and decision-making. Chapter 1 explores reasons behind the marginalisation of faith in studies on health and social care and the implications of this for social policy are discussed.

The second chapter explores the literature to offer reasons why religious beliefs and practices are relevant to health and self-care. The influence of faith in different contexts is considered, using the model described in the Introduction to this thesis, in order to further understanding of the relationship between religion, health and wellbeing. This is followed by an exploration of social policy initiatives to address health inequalities. Chapter 3 examines these initiatives and how far they address needs arising from the faith identity of Pakistani Muslims. A comparison between the initiatives introduced to address health inequalities and the findings of this study provide a basis for later discussion on the implications of the research for policy and service development.

The review ends with an exploration of the demographic profile of Pakistani and Muslim communities in the UK. This profile is derived from Census 2001 figures, the most comprehensive and up-to-date national statistics on the Pakistani and Muslim communities in the UK. These figures are presented as a further means of understanding how Pakistani communities relate to the wider population in terms of their health and wellbeing, both as an ethnic group and as part of a broader faith community.

Chapter 1: Understanding Religion

Given that exploring the influence of religion is central to the aims and objectives of this thesis, it is important to clarify what the concept of religion means and to examine different interpretations of its significance and the way it operates. This chapter explores these issues and offers possible explanations for the bias, highlighted in the introduction to the thesis, towards research frameworks that focus on ethnicity rather than religion. It begins by considering historical developments that have contributed to the paradigm in which healthcare research is carried out. The limitations that such developments impose on sociological inquiry, and consequently on social policy, are discussed and the complex relationship between religion and other concepts such as ethnicity, culture and spirituality is explored. The importance of religion to studies in health and social care is further examined along with the implications of paying attention to this aspect of identity and social life.

1.1 Religion, science and knowledge

There is evidence of a longstanding tradition in healthcare of separating religion from the illness experience. This has had the effect of marginalizing and stigmatising spiritual beliefs, so that patients may only reveal those parts of their experience that fit the normative expectations of clinicians (Walsh 1998). Patient narratives may consequently edit out the spiritual dimensions of their lives and render their own beliefs and practices invisible. At the same time, research into chronic illness conditions rarely focuses attention on such dynamics or explores how religious motivations affect an individual's attitudes or needs (Selway and Ashman 1998).

The practice of excluding religion from the realms of scientific inquiry has been linked historically to the 'Enlightenment' of seventeenth and eighteenth-century Europe as part of the process through which the power of the Church over the state was gradually eroded:

'the constitution of the modern state required the forcible redefinition of religion as belief, and of religious belief, sentiment, and identity as personal matters that belong to the newly emerging space of private (as opposed to public) lifeit has become commonplace among historians of modern Europe to say that religion was gradually compelled to concede the domain of

public power to the constitutional state, and of public truth to natural science... This construction of religion ensures that it is part of what is *inessential* to our common politics, economy, science, and morality.’ (Asad 1993 pp 205, 207)

Enlightenment notions of knowledge and truth were further developed through the modernist movement in science. The insistence on sensory experience as the only reliable source of scientific knowledge can also be traced back to these attempts to free science from the grip of official Church doctrine. Sense experience, available to everyone, was adopted as the sole source of scientific knowledge with the deliberate intention of excluding revelation from the scientific enterprise and thus freeing scientists from the control of the Church (Ragab 1993). Religious experience was thus simultaneously defined as irrational, unverifiable and scientifically meaningless (*ibid*).

The development of scientific inquiry in Europe, of which sociological studies are a part, were thus shaped and developed by European culture, ideology and politics. This development can consequently be understood as a social activity laden with values. The perception of religion within social science has been strongly influenced by these historical developments and its claims to truth have been denied through arguments developed during the Enlightenment period. Following on from this, early modernists formed a concept of knowledge as developing through a historical, evolutionary process and based on ‘maturity’, that is, reliance on one’s own reason instead of on another’s authority (Asad 1993).

Scientific knowledge, based on what is irrefutable, observable or explicable through human experience, was thus constituted as the pinnacle of truth. In contrast, religion was depicted by Comte, an early modernist, as a primitive form of knowledge - developing as social groups progressed through stages from animism to monotheism, eventually to be replaced by scientific knowledge gained through the exercise of reason (Pickering 1997). Religious beliefs were thus conceptualised as archaic, irrational and undeveloped. This concept of knowledge clearly denies status to religious beliefs and stands in stark contrast to religious concepts of knowledge through revelation.

‘in its basic ideological posture, positivism is thus worldly, secular, anti-theological and anti-metaphysical.’ (Asad 1993 p 877)

The notion of 'radical doubt', central to the nature of modernist ideas about knowledge and truth (Mellor 1993) also appear to carry an inbuilt antipathy towards tradition. Giddens reflects this perspective in his explanation of 'reflexivity': a constant monitoring and revision of beliefs and practices, which lead to greater self-awareness and development of knowledge (ibid). The continual and organised use of knowledge to re-order and transform itself is future-oriented and offers nothing to rely on in the past. (Ironically, modernity itself has been subjected to this process - the rejection of modernity and replacement with post-modernism could itself be described as a product of the 'radical doubt' perspective).

The possibility of absolute truth is rejected through such notions, which deny that any sources of knowledge are capable of being accepted as incontrovertible. Again, these explanations of truth and knowledge imply delusion on the part of those who accept revelation as valid knowledge. By requiring all beliefs to be open to constant revision, sociological analysis becomes unable to accept or deliberate on revelation or ultimate truths.

The lack of any reliable signposting to knowledge or truth opens up the possibility of multiple lifestyle options in which religiosity simply constitutes one possibility. Sociologists, both early and recent, have explained why a religious way of life might be adopted, by referring to the need for meaning. Without explaining the necessity itself, they acknowledge that religion may satisfy an inherent human need for meaning. Berger, for example, describes this as the 'inner compulsion of the human mind' to understand the world as a meaningful cosmos. The 'sacred canopy' of religion thus shelters individuals from the chaos of meaninglessness (Wuthnow 1986). Comte and Durkheim further highlight the ability of religion to act as a social force which binds individuals together and reshapes their identities as part of a collective (Mellor 1993). Moral power is described as arising from collective emotional solidarity and taking on a sacred quality because it is superior to anything experienced at an individual level. Rituals, feasts and ceremonies are perceived to replenish this collective energy and to fill people with contagious emotional energy at key times such as birth, maturation into adulthood, procreation and death.

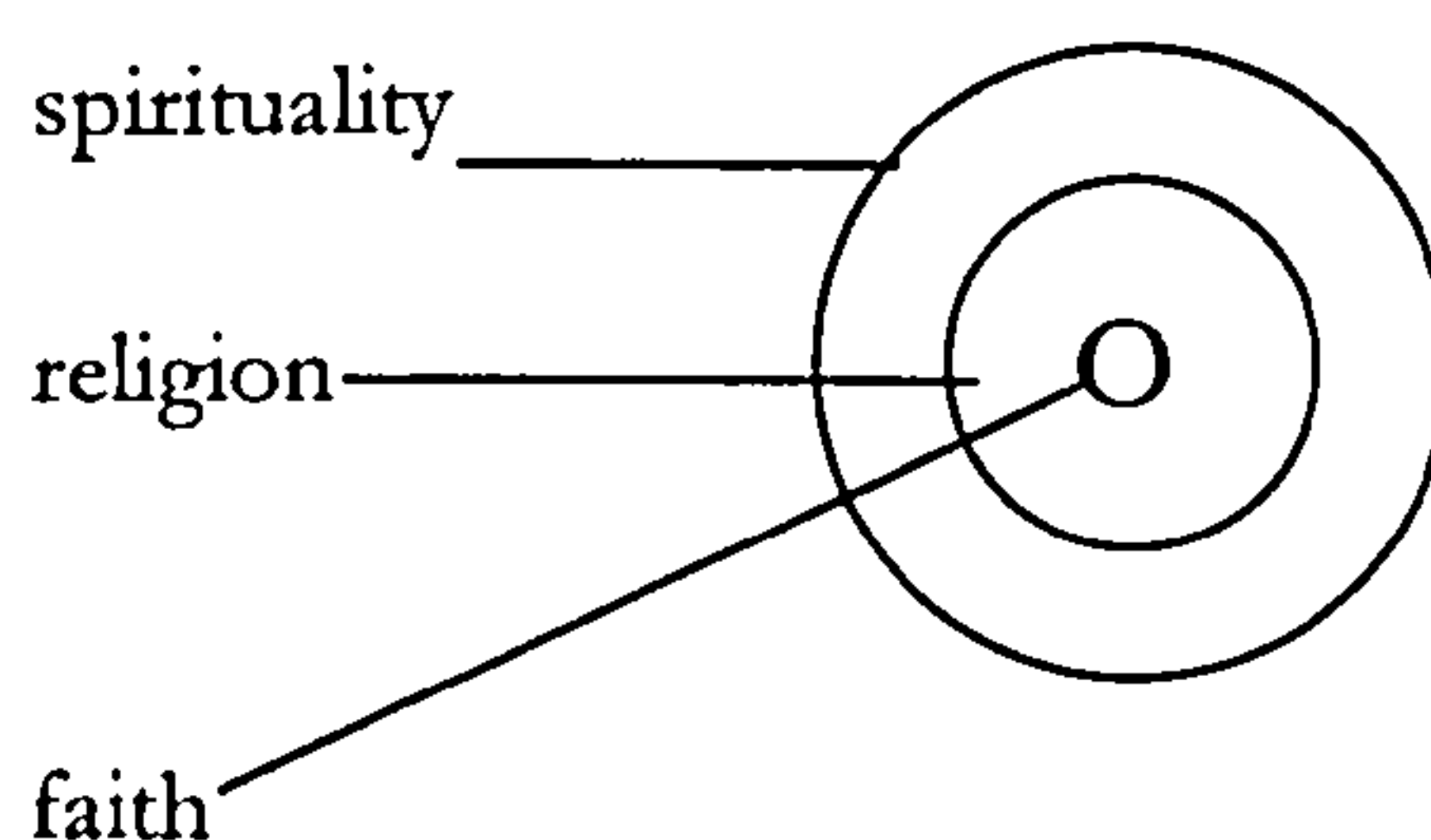
Despite Durkheim's use of abstract quasi-religious terms and his view that religion is 'a fundamental and permanent aspect of humanity', the elements of religion are described solely in social terms and his emphasis is upon social cohesion (Wuthnow 1986).

These explanations of faith are functional in nature and are based on the notion of religion as a social construction. This notion consequently influences the way religious practice is explained and interpreted. Religious rituals become symbols to be interpreted in relation to their social function rather than as self-contained acts interpreted in accordance with religious scriptures. Thus the practice of fasting is related to remembering the poor rather than to 'purifying the soul' (Asad 1993).

This restricted understanding of religion in relation to its human elements, combined with the view that all beliefs must to be open to constant revision, means that sociological analysis is unable to deliberate on supernatural forces or religious realities. To those who accept the teachings of a religion, sociological reductions explain away their 'paramount reality' (Wuthnow 1986) by attributing religious beliefs to social conditions.

1.1.1 Religion, faith and spirituality

Distinctions between religion, faith and spirituality are explored by Hull (1999) who suggests that these three form steps allowing individuals to transcend the biological towards 'the achievement of humanness'. He suggests they can be understood as three concentric circles: 'religion is the instrument, spirituality is the goal; faith is the attitude of trust that the instrument will lead to the goal':



Hull makes the point that faith may be understood differently within different religious traditions and therefore its relationship to transcendence (ie spirituality) may also be understood differently. This suggests that the nature and understanding of religious practice within a group needs to be explored and that the diagram above may be reordered for different faith communities. Both the lived experience and the scriptural authorities of a religion are likely to be relevant to this exploration.

In relation to Pakistani Muslims, the Qur'an and Sunnah³, constitute the most commonly accepted scriptural sources of authority on Islam (Surty 1995). These scriptures describe the goal of religion as 'taqwa', a state of God-consciousness which is attained through sincere belief in Islam and through incorporation of religious teachings into everyday life. This state of being or attitude of mind is 'the result of the penetration of faith into the heart' (ibid p17). Thus, according to Islamic scriptures, Hull's diagram is reordered so that faith is a second rather than first stage towards achievement of 'taqwa', with acceptance of religion being the first step in this process.

This is a very significant difference - the Islamic model promotes religion as a foundation on which faith can develop and allow individuals to 'transcend the biological towards achievement of humanness' (Hull 1999). The practice of religion is therefore presented as a vital element in fostering behaviour that can provide the conditions for faith, and subsequently for spirituality, to develop.

The scriptural sources also make clear that an awareness of God and of accountability for one's actions is central to an Islamic understanding of faith and spirituality (Philips 1995). Hull (1999), on the other hand, suggests that religion can be used flexibly and his model would include spirituality as experienced by an atheist or agnostic. "Taqwa' and spirituality may refer to similar states of being, however, the means by which this can be achieved are potentially so different that these two words cannot be considered as direct translations of each other. This distinction between religious and spiritual frameworks has been recognised in the wider literature on health and social care (Hatton et al 2004; Speck et al 2004).

The relationship between faith and religion described in this section is explored in order to highlight the different way in which these concepts are seen to relate to lived experience in Islamic and sociological texts. The exploration provides a further example of the influence of European culture on how religion is perceived in healthcare studies. However, this distinction between faith and religion is not carried through the rest of this thesis and the terms are used interchangeably.

³ see Glossary: Appendix 1

1.2 Ethnicity and religion

In view of the rejection of religious frameworks described earlier, it is perhaps not surprising that studies on health and healthcare within Pakistani communities have most often adopted the theoretical framework of ethnicity as a basis for research, whilst excluding or marginalizing consideration of the religious identity of respondents. As already highlighted, this has reflected a more general trend within studies of health and social care (Selway and Ashman 1998). Studies about the impact of religion on the health of Pakistani Muslims is limited by both these factors and the available literature is consequently sparse.

Within qualitative studies of ethnicity and health, group identities based on shared physical features, ancestry, geographical origins and social and political heritage have been used to define ethnic communities (Bhopal 1997). Such studies have been instrumental in highlighting the experiences of service provision and the healthcare needs that exist within minority ethnic groups. The value of studying ethnic variations has also been highlighted as a tool in aetiology (ibid).

Despite the widespread use of this framework, however, the use of ethnic groupings has been criticised by a number of writers. As a concept, ethnicity is recognised as underdeveloped in its ability to recognise diversity (Ahmad 1999). Thus studies are necessarily

'beset with qualifications and exceptions because [findings]... may not necessarily apply to groups which are 'heterogeneous'. A weakness within the field of ethnicity and health is that there is much data but little robust theory. Thus most research provides a set of conclusions to which there will be many exceptions'.

(Hillier 2001).

Conceptions of ethnicity as fluid and 'continually changed across contexts and over time' (Karlsen and Nazroo 2002) may add to the confusion by attempting to combine fixed and changing aspects of identity, such as geographical origin and religion, within the same concept.

A focus on racism has been largely absent from much health research, which has emphasised 'ethnic sensitivity' rather than the structural inequalities that lie behind the disadvantage of minority ethnic communities (Stubbs 1993). The model of race equality promoted is founded on the idea of benevolence and promotes increased professionalism and technical skills rather than a transformation of social relations (ibid).

Furthermore, the construction and use of ethnic categories, though often adopted by people from minority ethnic groups, has also been described as an essentially racist imposition by the dominant ethnic group, which has led to the possible racialisation of health research (Barot 1993; Dyson 1998). Specific ethnic categories, such as those developed for the Census, may not correlate with terms used by social groups for self-identification (Rankin and Bhopal 1999). Confusion surrounding ethnic categories can, furthermore, result in inconsistency and inaccuracy in the terms used to describe these groups (Bhopal and Rankin 2002). Contemporary definitions of ethnicity emphasise the need to unpack categories such as 'Asian' which imply homogeneity across wide geographical areas and to break the concept down into its different dimensions (Karlsen and Nazroo 2002).

Attempts have been made to include religion as a subset of ethnicity (Modood 1997; Nazroo 1997; Aspinall and Jackson 2004; Audit Commission 2004); however, the relationship between ethnicity and religion is not straightforward. Ethnic group categories (such as those used in the Census) focus on nationality, which, in the case of Muslims and some other faith groups, can mask religious identity. In areas such as diet and dress there is an overlap in the influence of ethnicity and religion – for example, Muslims from Malaysia and Bangladesh are likely to eat different kinds of food influenced by regional availability and traditions. Nevertheless, they will still share with each other and with Muslims in all other ethnic groups the principles of a *halaal*⁴ diet. In this respect, their food and drink will differ significantly from others within the same ethnic category who do not share their faith. Such variations in diet and regional traditions are clearly of relevance to healthcare.

There is evidence that health inequalities in South Asian communities can be revealed more accurately using faith identity than ethnic groupings: greater socio-economic and health

⁴ See Glossary: Appendix 1

inequalities exist between the different faith groups comprising the Indian population, for example, than between Indians and other ethnic groups. This is likely to be because Indian Muslims have more in common with the lifestyles, beliefs, customs and historical perspectives of Pakistani Muslims than with those of Indian Sikhs and Hindus (Ahmad 1999). This suggests that religion should be recognised as an aspect of identity that may at times overlap with ethnicity but cannot be subsumed by it. Both aspects of identity are important in terms of belonging and social relations and therefore both are likely to have a bearing on health and wellbeing. Ignoring the influence of religion in research means that only a partial picture will emerge of the issues affecting a particular social group.

The British Medical Association has recognised that shared ideas about health and illness affect health beliefs and notions about causation (British Medical Association 1995). There is also evidence that shared beliefs influence willingness to give and receive care and the perception of appropriate roles for those who are ill or disabled (Selway and Ashman 1998). Shared beliefs are implied rather than explicitly included in the definitions of ethnicity mentioned at the beginning of this section. However, common beliefs are the explicit and essential foundation on which faith communities are formed; the values and principles of a faith will necessarily permeate such communities at various levels. Within communities in which faith is an important aspect of identity, interventions that fail to address religious beliefs are, therefore, unlikely to comply with BMA guidelines about incorporating relevant health beliefs into treatment methods.

Within the wider literature on health and social care there is little to be found on the need to address religious beliefs in service provision. Indeed, attempts to introduce attention to this aspect of identity into service frameworks may meet with hostility and resistance (Hatton et al 2004). Interestingly, provision relating to palliative care and bereavement counselling appears to be an exception, though consideration of religious beliefs may be subsumed within the concept of spirituality (Speck et al 2004). As highlighted earlier, this concept is in some ways significantly different to religion.

Attention to religious beliefs is more common in studies of minority ethnic communities. The use of ethnicity as a framework within Pakistani communities, whilst restricting exploration of the influence of faith, may nevertheless result in findings that can be related

to faith identity, as the vast majority of Pakistani people are Muslim⁵. However, in studies using a 'South Asian' sample, the relevance of faith to research findings is more difficult to assess unless religious identity is specifically addressed. South Asian people belong to a range of religious groups, with some significant differences in values and beliefs about health, illness and communication. These differences are likely to affect lifestyle, communication patterns and decision-making as well as social networks and relations. Failing to analyse findings in relation to religious groupings may therefore mean that important issues in all these areas are not identified.

Studies that focus on ethnicity may result in findings that relate to faith only because participants raise the significance of their religious practice, rather than as a result of deliberate exploration and inclusion in the design of a study (see, for example, Cinnirella and Loewenthal 1999). Consequently findings of inequity are unlikely to differentiate between religious and ethnic discrimination. Yet, this important distinction is applied in practice within UK society. The concept of Islamophobia was coined in recent years to represent a particular form of racism experienced by Muslims and targeting their faith identity. Indeed racism within the UK has historically focused on religious practices, particularly those related to Islam. (Commission for Racial Equality 1998; Runnymede Trust 1997).

Furthermore, if needs are identified only within the conceptual framework of ethnicity, whilst minimising the significance of religious identity, recommendations for service development may fail to increase access to and take-up of services. In this case, ethnicity becomes an imposed framework that can result in misrepresentation or only partial acknowledgment of the kinds of needs that exist.

Minority groups have traditionally been obliged to accept such imposed categories and have packaged themselves according to state-created identities in order to secure resources and have needs met (Ahmad 1996). This has often meant hiding or compromising their prime identity (Barot 1993). Faith identity may not only be undermined in this way but the ability of religious values to make sense of the world and to be a valid foundation for self-organisation is simultaneously called into question.

⁵ 97% according to Nazroo (1997). Census 2001 figures show that 92.% of Pakistani people stated they were Muslim and 6.16% made no statement about their religion

Failure to acknowledge religious identity also means that the influence it can have on interaction is not addressed in professional training programmes. Professionals may consequently feel ill equipped to understand value frameworks other than their own (Hatton et al 2004). A disparity in expectations and an emotional distance between patients and professionals, and between professionals with different religious backgrounds, may result from this lack of engagement with alternative beliefs and values (Bhopal 1997). The quality of these relationships may subsequently suffer through mutual criticism (Bowler 1993; Murphy and Clark 1993). Studies show that such inability to form a holistic relationship may lie at the root of suboptimal care, poor take-up of services and other types of discrimination such as stereotyping (Auluck and Iles 1991; Bowler 1993; Vangen et al 1996).

There is evidence that health professionals have successfully used knowledge of beliefs that affect social action in various ways. For example, a campaign to reduce smoking after the end of Ramadan, was based on knowledge that Muslims would have reduced or finished their smoking habit completely during the month (Kelleher and Islam 1996). Knowledge of the links between religious beliefs and diet have also been used to aid the aetiology of stomach cancer which has different rates of incidence in different ethnic communities (Bhopal 1997).

Ethnicity and religion are thus both important aspects of identity that need to be acknowledged in any study of Pakistani communities alongside other influences such as age, gender and social class, which are also known to impact on communication and decision-making in people with chronic illness (Charmaz and Olesen 1997). A conceptual framework is needed therefore that encompasses all these elements and that can take account of the complex relationship between them.

The concept of culture can potentially provide such a framework. To do so, it would need to be understood as an overarching construct that can accommodate different aspects of identity, each of which may dominate at different times and in different contexts. The notion of culture would also need to incorporate external as well as self-definitions – what each aspect of identity means to the individual and social group as well as how it is understood by others. Whether this concept is capable of functioning in these ways is considered in more detail below.

1.3 Culture and identity

Culture has been described as:

‘a complex mix of beliefs, customs, morals, laws and past experience. It provides a background code of practice by which individuals live and a set of explanations to use in interpreting the world’ (Fisher 2001: p2.3)

‘structured by gender, class, caste and other contexts’ (Ahmad 1996: p190)

‘socially constructed and emergent’ (Robinson 2002 pxxiv)

These various definitions of culture suggest that it is a composite and fluid concept informed not only by religion and ethnicity but also by other group identities such as socio-economic class, age, gender and education. Culture may thus be operationalised at the level of the individual as well as of a social group and can relate to professional as well as community contexts. The different elements which contribute to individual or group culture may have more or less dominance as a result of contextual factors (such as legislation or geographical situation) and the way these affect social relations between people. In addition, self-definitions of cultural identity may have to compete with those imposed by others (Robinson 2002).

Within healthcare studies, the concept of culture, like ethnicity, has been used inconsistently. It has often been applied only to minority ethnic groups as a way of emphasising difference with the ethnic majority and frequent failures to distinguish between culture and membership of an ethnic minority has reinforced a racialised use of the term ‘culture’ (Robinson 2002). Confusion is also apparent in terms such as ‘religious and cultural identity’ which implies that religion does not inform culture, even though the definitions above clearly incorporate beliefs, values and meanings (Ahmad 1996). Culture and religious affiliation have also been described as subsets of ethnicity (Modood et al 1997; Nazroo 1997), adding to the inconsistent use of such terms.

Despite these difficulties, the concept of culture can help in theorising the influence of faith on health. The dynamic interaction between different influences on individual or group behaviour is helpfully contained by this overarching framework. The framework would allow exploration of instances where religion is more important than other aspects

of identity and those where other influences are more dominant. At the level of the individual such an approach may highlight particular areas of experience in which religion plays a key role and similarities or differences between individuals depending on their religiosity. At the level of a faith community, the influence of religion, as well as other aspects of culture, on social networks and communication patterns may be explored through this framework. How shared norms within a Muslim community are understood within the wider UK society can offer insights into the barriers and opportunities for effective communication in different contexts.

1.4 Conclusion

Exploring the influence of religion whilst acknowledging other aspects of culture allows the complexity of lived experience - for example, the interaction of religious as well as non-religious motivations - to be explored within an inclusive framework. This approach takes account of the multifaceted nature of people's lives. The dominance of ethnicity in health and social care research on Pakistani communities has blurred the significance of these other influences and resulted in partial and inaccurate representations of experience and need. This chapter has highlighted that sociological representations of religion, faith and spirituality may not accord with how these notions are understood in the lived experience of Pakistani people. The following chapter begins the process of developing a more accurate understanding of Pakistani communities by considering the way religion may influence individuals and communities in more detail.

Chapter 2: Understanding Religious Influence

In order to compare the lived experience of Pakistani Muslims with external understandings of religion, and of Islam in particular, it is necessary to examine the influence of religion on interactions in different contexts. As an aspect of identity religious beliefs may influence not only individual behaviour but also social structure. This chapter explores the influence of religion in both spheres and, in particular, how this influence is operationalised in terms of health. It also attempts to move forward - from understanding how religious identity has come to be excluded from health and social care, to finding areas of common ground between the two spheres.

As highlighted in the previous chapter, sociological descriptions of religion may differ from those offered by religious texts themselves. Nevertheless, both religious and sociological texts appear to agree that religious beliefs provide a master narrative that gives meaning and connection to human experience. These meanings are located in traditions and in significant historical events. The need for such beliefs is described both by sociologists and in religious texts as inherent in human nature. As a social force, religion provides shared meanings which bind individuals together and reshapes their identities (Mellor 1993). Religious beliefs and rituals have been described as the means of maintaining moral and social order within a society (Pickering 1997). This understanding of the role played by religion is shared by those who promote Islam and is supported by verses of the Qur'an:

'Divine laws represent guidance for humankind in all walks of life. They define right and wrong for them and offer human beings a complete system governing all of their affairs.... The divine laws command and prohibit various acts and substances to protect the human spirit, the human body and the human society from harm. In order for human beings to fulfil their potential by living righteous lives, they need to worship God through obedience to His commandments' (Philips 1995: p31).

‘Verily, this is my path, leading straight, so follow it. And do not follow other paths for they will scatter you about from God's path. That is His command to you in order that you may be conscious of God.’ (The Qur’an 6:153)⁶

‘Corruption has appeared on the land and in the sea because of what man's hands have earned, in order that God may make them taste a part of what they have done, and in order that they may return to the right path.’ (The Qur’an 30:41)⁷

Although the source of religious knowledge may be disputed, the above extracts demonstrate that there is common ground between religious scriptures and sociological texts in relation to the influence of religion on lived experience. References to achieving human potential and protecting human society echo sociological descriptions of religion and spirituality (for Muslims ‘consciousness of God’) highlighted in the last chapter.

The influence of religion is explored below at the level of the individual, within family settings and in the wider community. In this way particular sites and significant themes affecting religious influence, as well as any relationship with health and wellbeing are highlighted. Where possible, literature specifically relating to the Pakistani community or to Muslims in general is identified, however, the wider literature is also drawn on where gaps in evidence relating to these communities exist.

2.1 Influence on the individual

At the level of the individual, religious beliefs carry with them, in varying degrees, requirements concerning lifestyle (such as dress and dietary laws), ways of relating to others and activities of worship. Religious teachings on relationships and interactions with others may cover a wide range of actions. The way to greet another person, the timing and nature of exchanges, non-verbal communication and forms of expression are all legitimate areas for religious instruction (Radley 1993). Religion may thus shape the speech of people from a particular faith group, and this in turn reflects the particular concepts of health and illness, which guide their thoughts and actions (Williams G 1993). Faith beliefs exist within cultural and social contexts, which also influence relationships and interactions and, as already highlighted, there is considerable overlap between age, gender, social class, ethnic

⁶ See Pickthall 2000

⁷ see Pickthall 2000

and religious influences (Modood et al 1997). Although these may be considered separately, within everyday experience they are essentially interconnected.

An example of such overlap is the existence of inter-generational differences in the practice of religion, which appears to affect some faith communities more than others (ibid). Gender differences have also been demonstrated in relation to the influence of religion on daily life: most South Asian males do not express a preference for male doctors, perhaps because this preference is more likely to be met anyway, however they do appear to support the idea of women having access to same gender staff. More than 90% of the Asian sample in one study said they felt more female health professionals should be available (Shah and Piraka 1993). How far religious beliefs are involved in such preferences is difficult to assess accurately where the sample is defined in terms of ethnicity but become apparent when religious identity is acknowledged (Bowes and Domokos 1996). Patient preferences are likely to be affected further by their degree of adherence to religious practice. It has been suggested that the degree of difference between certain beliefs or values and those dominant in the majority culture may be another factor influencing such preferences (Modood et al 1997).

The cognitive influence of religious beliefs is also significant. In the context of illness, such beliefs invite an expansion of awareness from local to universal concerns. This transpersonal aspect of religion provides experience of a deeper meaning and a transformed sense of self to people with chronic illness (Walsh 1998). Religion may define a condition positively, giving the experience meaning and purpose and providing knowledge of how to respond in such circumstances. These teachings can act as a source of energy to patients (Ahmed A 2000). Alternatively, religious beliefs may encourage negative interpretations, for example, of illness as a punishment. Such punitive interpretations have been found to damage patients' ability to negotiate their condition and to have a harmful influence on the self-concept of people with chronic illness (Selway and Ashman 1998).

There is evidence that the meaning and thus the implications of chronic illness may differ considerably between professionals and individuals from minority ethnic backgrounds and faith values are presented as one reason for this disparity (Hill 1994). The difficulty of communicating concepts based on faith to health professionals who focus primarily on physical health is clear. In relation to mental health, common references to 'aches and

pains' and 'heartache' may reflect an attempt to articulate the experience of depression in a form that is seen as appropriate to the situation and understood by clinicians but which may also demonstrate confusion about how to think about the emotions involved (Ahmed A 2000).

Medical explanations about the cause of a condition may be differentiated from explanations about why (in terms of meaning) a condition exists. These explanations may be formulated in the light of personal biographies and other sources of knowledge, including religious beliefs and family or community norms (Williams R 1993). Individually or socially held beliefs may at times conflict with medical explanations: professional attitudes towards mental illness and towards consanguineous marriages are good examples of conflicting medical and social interpretations. It has been suggested that such conflicts may lead to confusion as people struggle to make sense of their situation (ibid).

Understandings of the relationship between the individual and society may also be an area in which belief frameworks differ. The Islamic view that individuals are responsible for their behaviour is held alongside the recognition that societies and individuals have equal co-existence and that individuals influence and are influenced by each other. The wellbeing of an individual is thus closely related to the wellbeing of society (Al-A'ali 1993). This understanding is not supported by a professional culture, which may emphasise the role of the individual in decision-making, without addressing social influences on action and choice (Dyson 1999).

Failure to recognise the cognitive frameworks of service users in professional practice has been shown to cause problems in Muslim populations. Al Dabbagh (1993) documents the difficulties caused by following the Western model of social work practice in an Islamic cultural context, in the belief that professional practice is universal. The model failed largely due to its exclusion of religious values and spiritual aspects of life, which were of great importance to service users. These problems have prompted questions about how to reorient social work practice from an Islamic viewpoint. This perspective suggests that one's relationship with God affects all aspects of life and that adhering to correct belief is a means of preventing personal problems. A new paradigm and reoriented approaches would thus involve intervention strategies that address service users' worldly concerns and improve their spiritual life.

2.2 Influence on family life

Within Muslim communities, families are commonly seen as the strongest bond of association (Sheikh and Gatrad 2000) and research within the Leeds⁸, Pakistani community provides evidence that family relationships have been the building block for the establishment of this community (Geaves 1995). Within families, clearly defined roles may be apparent; fathers are most often responsible as breadwinners and mothers primarily responsible for running the home (Wheeler 1998). Religious teachings clearly support this kind of family organisation:

‘Each one of you is a guardian - a man is a guardian of his family and a woman is a guardian of her husband's home and children.’ (Hadith 3.733: Khan 1987)

Census figures in relation to economic activity amongst Pakistani women (see chapter 4), reflect this understanding of family roles. For many women from Pakistani families their role within the family has been found to be more important to them than education and employment. Mirpuri people (who constitute a significant proportion of the Pakistani community in the UK) are described in one study as probably the most home orientated of Asian migrants to Britain (Wheeler 1998). It is unclear whether this level of social contact is preferred, as constricted opportunities for social interaction have been reported, especially amongst middle-aged and older women (ibid). The roles and dynamics described do, however, accord closely with Islamic teachings on the importance of the family to a healthy society (Ibrahim I 1997).

The influence of family members on health-seeking behaviour amongst Pakistani people living in the UK and the way in which this is exercised, is an under-researched area. Studies which do explore these dynamics often focus on gender roles and particularly women's position within the family. These have been shown to affect access to information and contact with healthcare providers. Pakistani men, for example, in both urban and rural settings in Pakistan are more likely than their wives to know how to obtain healthcare (Mahmood and Ringheim 1997). A number of studies show that this situation is mirrored in the UK with men taking a lead role in contact with health and social care practitioners (Mir and Tovey 2003; Ahmad 2000). However, this may be an enforced

⁸ the city in which the study was conducted

position arising from greater fluency in English amongst men (Mir et al 2000). There is some evidence that women's decision-making on health issues may be influenced by men: the attitude of husbands, for example, may significantly affect South Asian women's decisions about whether or not to consult a male general practitioner (Bowes and Domokos 1996). The prospect of dishonouring the family and being ostracised can also be a powerful constraint on women's choices in this community (Wheeler 1998). However, research is limited as to whether such constraints are gender specific and whether they reflect religious or other influences.

As in the wider literature on caring, studies of South Asian carers reveal notions of duty, obligation, and responsibility, which work against the idea of caring as a burden (Katbamna et al 2000). At the same time, such family and community-held values may prevent open expression of carers' own needs and affect take-up of services such as institutional care and short-term breaks (Chamba and Ahmad 2000). The imposition of an overwhelming sense of moral obligation, emphasised by family and community members, may leave very little room for carers to negotiate their responsibility (Katbamna et al 2000). Again the origins of such notions are unclear. Religious teachings in Islam appear to allow a more complex understanding of rights and responsibilities so that a duty of self-care is balanced against expectations of being cared for by others (Taha 1993). How far these teachings are used to explain or negotiate family and community expectations is also an under researched area. A clearer understanding of the significance of these teachings to people within the Pakistani community would help to promote services for carers and people with chronic illness in ways that are likely to accord with accepted norms.

Caring responsibilities, particularly towards parents and young children can be traced to Islamic scriptures⁹, although these may not be the only influences on values associated with caring. This kind of support may be carried out within extended family settings, which have been shown to provide social, emotional and psychological benefits for grandparents and children (Sonuga-Barke and Mistry 2000). Wider relationships within the *biraderi* (kinship network) give similar psychological security and emotional support at times of stress (Ahmad 2000). However, a greater risk of mental health problems has been found for mothers living in such households (Wheeler 1998). Various reasons have been

⁹ This term is used to refer to the Qur'an (the book of revelation in which Muslims believe) and the traditions of the Prophet Muhammad (collected in books of Ahadith). See the Glossary (Appendix 1) for further explanation of these terms.

suggested for this including the loss of agency mothers may experience. Other factors have not been discounted however, such as the need for extended family living itself arising from the mental illness of a mother (Sonuga-Barke and Mistry 2000).

For many Pakistani families, migration has reduced the influence of the extended family in structuring family affairs. Many second-generation families will have grown up in nuclear families and will not have direct experience of extended family living (Dhami and Sheikh 2000). Economic hardship has led to fewer resources being sent to support relatives abroad and greater concentration on creating family structure and community in the UK. The increased entry of women into the workforce has also contributed to a re-evaluation of their role in society (Husain and O'Brien 1998). There is evidence that such cultural shifts may lead to situations of conflict between competing roles and responsibilities (Matsuoka and Sorenson 2001).

There is often little exploration in studies such as those outlined above of the origins of these aspects of culture in Pakistani communities. The particular influence of religion is not differentiated in these studies from other influences on beliefs and values. However, identifying religious as opposed to other influences on values and behaviour may be useful to health practitioners for a number of reasons. Interventions to improve health outcomes may assume religious causes of health behaviour when these have not been measured and when other influences, including the effect of environment, have been ignored (Nazroo 1997). Resources may consequently be used inappropriately and wasted because the causes of ill health are not accurately identified.

Furthermore, religious teachings may not support, and may even conflict with, common practices and expectations within this community. They may, therefore, provide a resource for health practitioners to draw on in terms of health promotion and negotiation of treatment. As already highlighted, faith beliefs constitute the most dominant aspect of identity for Pakistani people, traversing age and gender boundaries (Modood et al 1997). Values that are rooted in religious teachings may consequently be held more strongly than those from other sources and may be helpful in promoting interventions, for example, to reduce smoking or obesity. Religious principles, such as avoiding self-harm, may thus provide a positive counter to harmful social practices, such as smoking, that derive from other sources. Adopting concepts upheld by religious teachings to address health inequalities would offer a dual message – that the religious identity of the Pakistani

community is acknowledged and valued and also that particular values accord with evidence-based practice.

The diversity of values and beliefs within this community may thus be drawn on to help formulate appropriate responses to healthcare problems that exist at family and community levels. For example, there is evidence of family and community stigma attached to mental illness, which may extend to the children, spouses and in-laws of Pakistani women with mental health problems. These dynamics have been shown to add to the illness experienced by women who suffer increased stress and feelings of uselessness and despair (Sonuga-Barke and Mistry 2000). Such a response to mental illness appears to result partly from the loss of ability to fulfil responsibilities towards family members laid down in religious teachings. However, these same teachings may also be a source of principles which counter such stigma – such as a duty to visit and show concern for the sick and not to blame those who are ill for their illness (Taha 1993). Religious beliefs may also be a powerful source of cognitive therapy that can be used to help individuals deal with stress, anxiety and depression (Sheikh and Gatrad 2000).

The effect of environment on the ill health of individuals in Pakistani communities is a further under researched area (Nazroo 1997). The culture within these communities, as highlighted earlier, is not simply an internal affair: interventions may need to address external responses to religious identity if these also contribute to health inequalities. The evidence on religious discrimination is explored later in this chapter and in Chapter 4.

2.3 Influence outside the home

2.3.1 *Within the Pakistani community*

The consequences of being part of a faith community have, for some groups, been shown to influence access to healthcare. A study of information networks relating to contraception and reproduction found that adherents of well-established large urban churches had more intensive and diverse channels of information, both inside and outside their congregations, than women who were excluded from such networks. As a result, they participated more actively in the exchange of information about choices open to them (Agadjanian 1996).

The concept of neighbourhood is an important one in Islam, affecting relationships between Muslims and with others positively through encouraging mutual concern (Assar

1998). There is evidence that faith can act as a mobilising force within Muslim communities (Barot 1993) and that this can be harnessed to address social issues. A study based in Kenya showed that an Islamic response to problems faced at a community level may provide constructive alternatives which could not be achieved by secular organisations, based on encouraging particular codes of behaviour and the use of local networks (Beckerleg 1995). There is evidence that such alternative approaches have also been developed on a small scale in the UK voluntary sector (Mir and Tovey 2003).

In terms of health promotion, it has been suggested that use might be made, for example, of Islamic teachings on the body as a trust from God to promote the idea of personal responsibility, preventive healthcare and an active approach to seeking out advice for health problems (Ahmed A 2000).

Although some religious communities have been shown to provide practical support to families within their congregation (Selway and Ashman 1998; Walsh 1998), this has not been demonstrated at a practical level for South Asian communities. There is evidence of moral support, however, and religious communities may serve as a primary means through which individuals adapt to illness (Mir et al 2000; Cinnirella and Loewenthal 1999). Narratives from religious scriptures, passed amongst members of a faith community, have been shown to help promote positive examples of others who model resilience within families and communities (Mir and Tovey 2003; Walsh 1998). They may also serve to transmit cultural and family beliefs that guide personal expectations and actions. Anecdotes about the experience of other people may serve a similar function. A study of South Asian carers found that such anecdotes could reinforce carers' fears about the quality of care in hospital settings as well a moral obligation not to 'give away' the person cared for (Bhakta et al 2000).

Although, as mentioned earlier, religious beliefs may become harmful if rigid and punitive, they more often act as a resource for families and may be integral to the wellbeing of patients and carers. A number of studies have shown that religious orientation plays an important role as a coping strategy in the lives of carers from many ethnic groups (Atkin and Ahmad 2000; Mir et al 2000; 2003). In addition, religious factors are associated with beneficial effects on health and wellbeing in patients with blood pressure and those needing long-term haemodialysis (Selway and Ashman 1998). Faith, prayer and spiritual rituals, especially at sites of high spiritual energy such as places of pilgrimage or worship, have also

been shown to aid healing by triggering emotions that influence the immune and cardiovascular systems (Walsh 1998).

It is known that religious groups and movements sometimes operating on a national or international level, are accessed by Muslim people in the UK, often through electronic means (Drozdikova 1999). The wider literature on patient communication indicates increasing use of the Internet as a resource for advice and information on health issues (Tetzlaff 1997). The overlap between religious sources of information and the health beliefs and behaviour of Pakistani people has not been adequately researched. However, given the significance of religious beliefs and affiliations to this community, it is likely that they play an important part in the way Pakistani people negotiate chronic conditions and there is some evidence of this in the field of mental health (Cinnirella and Loewenthal 1999). The social organisations operating within communities are likely to reflect this emphasis and individuals may actively seek religious sources of information and advice in relation to their health. The influence of such sources on health-seeking behaviour and management of chronic illness is thus of considerable importance and requires further exploration.

2.3.2 Within the wider society

In contrast to the largely positive influence of religious beliefs at an individual, family and community level, there is evidence of a lack of understanding and deliberate discrimination in relation to Muslim communities within the wider UK society. A report on Islamophobia (Runnymede Trust/Commission on British Muslims and Islamophobia 1997) highlighted that Muslims face a degree of discrimination which does not appear to be mirrored in other social/ethnic groups, related to their beliefs. This makes the experience of Muslims different to that of other minority groups - as well as discrimination based on ethnic origin, their attempts to maintain beliefs and practices that differ from those dominant in the UK is a significant further source of prejudice.

Islamophobia has historical roots dating back to the Crusades, however the strength of hostility which exists at present does not appear to be greatly diminished despite the passage of time (ibid). A CRE survey of attitudes towards ethnic minorities found that all negative stereotypes documented referred to Muslim practices. These appeared to be associated with a perception that Muslims were 'invading' the UK and their refusal to integrate rather than their colour was the main obstacle to acceptance. These findings

suggest that the status of individuals and groups in UK society depends on how far they possess attributes valued by the majority. The degree of Muslim deviance from these attributes and their maintenance of a 'foreign culture' appears to arouse more resentment than prejudice based on colour alone (Commission for Racial Equality 1998).

Said's (1995) study of Orientalism can be seen as a history of Islamophobia in Europe and the means by which this has been maintained in popular thought. Through a wide-ranging analysis of texts dealing with Islam and Arabs and dating from medieval to contemporary writing, he demonstrates that these writings present an imaginative rather than factual account of their subject matter. His exploration of Western conceptions of 'the Orient' reveal that, despite posing as objective and impartial historical analysis, the majority of Orientalist literature adopts a profoundly anti-empirical approach, particularly towards Islam and Muslims. Thus, for example, Muslims are represented as a monolithic community of orthodox believers rather than as diverse communities in which interpretations of Islam are debated and contested 'in a dialogue of equals' (p338). Such literature repeatedly attempts to demonstrate the latent inferiority of Muslims and to turn Islam 'into the very epitome of an outsider' (p70). This construction is made possible by denying credibility to both, using the notion that Islam and Muslims are incapable of self-analysis or of constructing their own formulations:

'Assertions made about Islam [are] not made on the basis of evidence internal to Islam, but rather on the basis of a logic deliberately outside Islam ... Evidence of the Orient was credible only after it had passed through and been made firm by the refining fire of the Orientalist's work.' (p280 - 3)

Said suggests that Orientalist literature is designed to be read by Western audiences rather than by the people about whom it is written. The representations of Islam and Muslims and their relations with 'the West' support the idea of 'fixed identities battling across a permanent divide' (p336). He traces the origins of this notion to the medieval European interest in Islam, which 'derived not from curiosity but from fear of a monotheistic, culturally and militarily formidable competitor to Christianity' (p344). These writings have attempted not only to describe but also to dominate and defend against the Orient, and in particular, Islam. Thus descriptions of Muslims have historically served the purpose of political propaganda to support imperialist activity. He notes that modern Orientalist

literature parallels the acquisition of vast Eastern empires by Britain and France and has been used to justify colonialism.

As such, this literature forms part of a discourse of power that has contributed to national formulations of identity in Britain. These formulations are of vital importance in social debates involving concrete political issues such as immigration laws, the character and content of education and the direction of foreign policy. The continuing presentation of Islam as a binary opposite in this formulation is reflected in media stereotypes 'that lump together Islam and terrorism, or Arabs and violence, or the Orient and tyranny' (p347)

Said rejects the idea that to criticise Orientalism is to be a supporter of Islamism or the notion of a 'clash of civilisations'. In his analysis, the struggle to reformulate historical experiences between 'East and West' involves resisting the idea that these represent an eternal order and that difference implies hostility. He maintains that the geographical separations of people and cultures that once supported such notions no longer exists:

'cultures and civilisations are so interrelated and interdependent as to beggar any unitary or simply delineated description of their individuality. How can one today speak of "Western civilisation" except as in large measure an ideological fiction ...?'

(Said 1995 p349)

Evidence of Islamophobia and the continuing discourse of Orientalism is reflected on a smaller scale in a study of the Pakistani community in Leeds. Geaves (1995) describes the resistance to faith-based organisation by service providers and the general population alike. The community was, for example, unable to secure funding or premises for groups established on the basis of faith identity. The setting up of a mosque was delayed partly because of difficulty in raising sufficient funds and partly because 'No-one in the city was prepared to sell the Muslims a property which could be converted to use as a mosque'.

At the same time as self-organisation was limited in this way, mainstream services further undermined faith beliefs by failing to adapt to the religious requirements of Muslims. Resistance from both funders and providers of services meant that this particular Muslim community had insufficient resources to meet its own needs and was obliged to engage

with hostile service providers to address these. Geaves' study reveals that education was a particular area of concern for Muslim parents who found themselves:

'battling with the authorities to introduce Friday prayers in Batley High School. Schools in the area also found it difficult to supply halal meat and to understand why the Muslim children would not eat dinner during the month of Ramadan. Conflicts also arose over school uniforms and standards of dress during games and sports.'

(Geaves 1995 p14)

The study provides evidence that members of the Pakistani community in Leeds were, nevertheless, actively engaging with the wider society. One interviewee was co-founder of an interfaith organisation, for example, and the caretaker of the Islamic centre described conducting parties of schoolchildren around the mosque and explaining the basics of Islam to them. By the late 1980s he was giving talks to statutory services and church groups and advising prison services on race relations. He was also the first Muslim magistrate in the city. The study also highlighted the community's longstanding involvement with researchers with the first recorded study dating back to 1965.

A number of respondents were married to English women and the lifestyle they subsequently adopted was affected by British culture. Geaves claims that the 'attitudes and influences of these men were to radically affect the development of the Muslim community in Leeds' (p7). He suggests that contact with non-Muslims 'contributed to the moderation of the Leeds Muslim communities, despite the increase in religious and ethnic awareness' (p16).

Geaves presents a failure to accept UK culture as evidence of extremism. He points to Dewsbury as an example, where members of one religious organisation:

'have remained isolated from the culture of the receiving nation. The organisation has encouraged its members to focus completely on the practice of Islam and has condemned watching television, videos, reading newspapers and listening to the radio.'

(Geaves 1995 p16)

The study itself presents no evidence to support the notion that rejecting these activities leads to extremism or social isolation. The one interviewee who was from this organisation is described as:

‘active in the wider community, as a lay visitor for the West Yorkshire Police Authority and a member of the police forum. He has also been Deputy Chairman of the regional transport authority's passenger committee in West Yorkshire, the co-ordinator of his local neighbourhood watch scheme and a committed member of the Headingley Community Association.’

(ibid)

Geaves' assumptions may thus be seen as an example of the discourse highlighted by Said (1995), in which Islam is seen as inferior and potentially threatening to Western culture, necessitating supervision and dilution. Whilst providing useful information about the development of the Pakistani Muslim community in Leeds, his interpretation appears to contain elements of Orientalism in its perception of Islam as antithetical to Western culture and inclined towards extremism. This analysis is taken for granted, as though it requires no explanation or supporting evidence, but is simply and generally accepted as a well known fact.

2.3.3 Interactions with Healthcare Providers

There is considerable evidence that the needs of Pakistani communities in the UK are often not addressed by health and social welfare services, resulting in inappropriate provision and consequently low take-up of services (Chamba et al 1998; Acheson 1998). Institutional racism has been a fundamental force in the difficulties faced by these communities and studies have highlighted both ethnic and religious discrimination. For example, stereotypes of South Asian families who 'look after their own' are sometimes used by service providers to explain low take-up (Atkin and Ahmad 1998). There is little evidence that families are in fact able to be self-sufficient in providing care, however studies within South Asian communities do reflect a perception of duty amongst carers towards those for whom they care. Institutional failure to encourage take up of services may thus exploit and reinforce carer values and sustain inequalities in access to provision (Mir et al 2000; 2003).

This failure to develop inclusive provision is reflected in a number of areas. Services may be culturally inappropriate in terms of diet, activities and staff (Katbamna et al 2000, Chamba et al 1998, Hatton et al 1998). It is difficult to tell from existing studies how much such discrimination involves religious prejudice, however there is evidence that Pakistani people may experience racism in a particular way, related not only to colour, but to ideological differences that influence their way of life and increase their visibility (Commission for Racial Equality 1998). Their construction of need may be seen as differing significantly from prevailing customs and there may be resistance to the idea that these different norms should be accepted. A number of studies show, for example, that healthcare professionals often emphasise the alien nature of certain practices and their unacceptability in the British context (Bowler 1993; Chamba and Ahmad 2000).

As a central aspect of personal identity, it is likely that religious beliefs will constitute a significant influence on the health behaviour of Pakistani individuals. Islamic teachings may lay down codes of behaviour in the context of illness that encourage, for example, visiting and caring for a person who is unwell. The extent of family and community involvement in healthcare may, however, be viewed as inappropriate by those upholding the dominant culture within a healthcare setting (Murphy and Clark 1993). There is evidence that where religious practices are criticised by professionals and blamed for health or social problems, this may pose a threat not only to an individual's sense of self, but also to that of the family and community to which he or she belongs. Such criticisms may be met with both self-doubt and guilt or with scorn and accusations of prejudice (Ahmad 2000; see also Dwyer 1998).

An emotional distance between patients and professionals may result from such mismatched expectations, resulting in professional unwillingness or inability to form a holistic relationship with individuals for whom they are providing healthcare (Bowler 1993). There is evidence that this can lead to rapid deterioration in communication, depersonalisation and subsequent failure to provide adequate care (Kaufert 1999). Pakistani women in Norway, for example, have been shown to receive less analgesia in labour than Norwegian women (Vangen et al 1996) and in the UK, there is evidence that nurses' perceptions of South Asian women can determine whether they are offered referral to a social worker (Auluck and Iles 1991). Studies show that negative moral judgements may be made by professionals and lead to questions about the right of certain people to healthcare (Schott and Henley 1996). It has been suggested that the reluctance of

individuals from minority ethnic communities to take up healthcare services may be a consequence of this professional failure to relate to them at an emotional level (Vangen et al 1996).

These studies suggest that emotional or holistic engagement requires a degree of shared understanding and some shared values and that these form the basis of positive relationships between patients and professionals. It is not surprising, therefore, that Pakistani Muslims may hold a strong preference for professionals from their own community, emphasising the difficulties of 'difference' and believing that same 'race' professionals better understand the context in which they live (Cinnirella and Loewenthal 1999). People may feel that such professionals have an awareness of patients' socio-cultural milieu and the pressures they face as well as an ability to understand the specific symptoms of mental illness that they experience. The use of religious practices as part of therapy, seen as a useful resource for treatment, was considered by Pakistani people in one study as only possible with professionals who shared the same faith background (ibid).

Cinnirella and Loewenthal's (1999) work raises important issues but shows some confusion between 'race' and religious beliefs, which, as highlighted earlier, are not equivalent. Furthermore, differences in the interpretation and practice of religion within a faith group and how this influences patient preferences are not explored in the study leaving many questions about inter-group diversity unanswered (ibid). Without some investigation of the nature of religious practice within a faith group, responses to particular experiences may be assumed as having a religious cause when other motivations are equally relevant; Muslim communities in particular have often suffered from such generalised assumptions (Muslim Council of Britain 2002). Conversely, failing to accept the significance of religious identity may lead to denial of its impact (Halliday 1999). A more differentiated approach to the influence of religion would help avoid generalisations that would not necessarily apply to many members of a faith community.

Personal religious beliefs may influence professionals as well as those who use healthcare services. There is some evidence that interpreters or link workers who share an ethnic or faith background with patients feel a sense of responsibility for them and may consequently fail to translate or pass on information that could stimulate a hostile response (Lago and Thompson 1996). A link worker can thus act as an advocate not only for an individual but also for the religious or ethnic group to which they both belong. However, little is known

about the perspectives of professionals from particular faith backgrounds and the effect of religion on their interactions with colleagues and patients. This area requires further research as doctors, link workers and interpreters who share the same language or culture as their patients are often selected specifically for these reasons (Ahmad, Kernohan and Baker 1991).

2.4 Conclusion

This chapter has demonstrated that religious beliefs can influence cognition and choice and that religious identity co-exists with, and is balanced against, other aspects of the self, each of which may be more or less significant in different contexts. The way research is conducted in the Pakistani community, however, often blurs the distinction between religious and other influences. As a result of this, the relationship between religious identity, social action and health beliefs is unclear in most studies of the Pakistani community. The influence of religious teachings on caring, for example, may be bound in with economic and gender influences and experiences related to migration. Exploring each of these influences in its own right can prevent an approach that inappropriately privileges one influence and uses it to explain everything, whilst ignoring the diversity that may exist within a community. Attention to diversity is important also in highlighting the different ways in which religion may be practised and the different levels of religiosity within a faith group. Treating Muslims as a homogenous group has been one of the ways in which Islamophobia has gained currency in European contexts.

Understanding of Islam in the UK is based primarily on a historical tradition of dominating and defending against this creed rather than on an evidence base that gives a voice to Muslims themselves. Perhaps because of this, there is very little literature that shows how Muslims make sense of and interpret their religious beliefs in relation to health. A lack of empirical evidence about this aspect of their lives exposes Muslims to stereotypes and discrimination. Current practices in the UK continue this historical tradition by refusing support to faith-based organisations or to the practice of Islam in social contexts. The literature suggests that 'integration' is not perceived in the wider society as a two-way process that is negotiated between Muslims and other social groups, but as assimilation and adoption of the dominant culture in the UK. Failure to 'integrate' in this way appears to be the main reason that Muslims suffer discrimination that is distinct from racism based on skin colour. Such discrimination prevents empathy and the ability to develop an emotional

relationship, which is considered important by people with chronic illness and healthcare professionals alike.

This chapter does, nevertheless, offer some hope that these dynamics can be overcome. The common ground that exists between the religious teachings of Islam and the aims of healthcare offer a starting point for change. There is some evidence that healthcare interventions can validate and draw on the religious identity of Pakistani Muslims whilst, at the same time, improving health outcomes.

The dynamics of communication in healthcare settings highlighted in this chapter are rarely acknowledged by professionals, who tend to focus on linguistic differences and fail to view communication as something in which they are themselves participating (Mir and Din 2003). How social policy deals with religious discrimination will influence professional attitudes towards the issues highlighted in this chapter and the quality of interventions to address them. The next chapter examines a number of key policies and the attention they pay to the various causes of health inequality.

Chapter 3: Social Policy and Health Inequalities

The two preceding chapters have explored, from a variety of perspectives, the way Muslim beliefs have historically been understood. They have suggested that attempts to 'privatise' or marginalise religion has led to research that often fails to address religious identity or to acknowledge the impact of religious discrimination. This in turn has led to a partial picture of the context in which Pakistani Muslims live and of the possible causes of health inequality to which they may be subject. In this chapter, I will examine the consequences of this failure for government policy on inequalities in health. I will consider a range of national policies and initiatives to address health inequalities and explore their treatment of different causes of discrimination. Social class, age and gender, as well as religious and ethnic identity, will consequently be included in this exploration.

The overview aims to provide the policy context in which the needs of Pakistani people with chronic illness have been formulated and addressed. This will enable findings from the study to be considered, not only within the frames of reference of respondents themselves, but also within the wider framework of Government approaches to health inequality. Policy drivers influence professional practice and stimulate change to such practice. Identifying any mismatches between these drivers and the perspectives of respondents in the study will allow new approaches to be suggested that may better address health inequalities in a group which appears to have benefited least from current approaches.

As highlighted in Chapter 1, the traditional separation of religion from healthcare has resulted in policies that focus more on ethnicity than on religious identity when the needs of Pakistani communities are addressed. Policy treatment of these aspects of identity are therefore discussed separately in the following sections. Other causes of health inequality, such as social class and age, are incorporated in each section, where appropriate.

3.1 Ethnicity and health inequalities

Building on a large body of evidence about ethnicity and health, the Acheson Report on Inequalities in Health (1998) presented its findings within the framework of ethnicity, social class and gender. It acknowledged the higher mortality and morbidity rates affecting some minority ethnic communities and emphasised the need for 'cultural competence' in service

provision. The report also indicated the need for a shift from recognising unmet need to taking strategic action and prioritising this action at all levels of social policy:

‘We recommend that the needs of minority ethnic groups are specifically considered in the development and implementation of policies aimed at reducing socio-economic inequalities...’

‘We recommend the further development of services which are sensitive to the needs of minority ethnic people and which promote greater awareness of health risks...’

‘We recommend the needs of minority ethnic people are specifically considered in needs assessment, resource allocation, health care planning and provision.’

(Acheson 1998: Recommendations 31-33 pp 97 and 100)

Despite these strong recommendations, the NHS Plan (Department of Health 2000) , published two years later, failed to give this consistent priority or strategic attention to minority ethnic communities. Strategies to deal with health inequalities emphasise poverty with far more consistency than additional barriers to healthcare that are more specific to minority ethnic groups. The Plan does make reference to differences in health between ethnic groups, for example:

‘children of women born in Pakistan are twice as likely to die in their first year than children of women born in the UK.’ (ibid: paragraph 13.15)

However, it does not go the step further advocated by the Acheson report, to strategic action that addresses ethnic health inequalities. The majority of the Plan’s initiatives to reduce child mortality, for example, focus on programmes that target children living in poverty and ‘the longstanding gap in infant and early childhood mortality and morbidity between socio-economic groups’ (ibid: paragraph 13.5)

The Plan envisages that local NHS action to ensure equitable access to healthcare will be measured and managed through the NHS Performance Assessment Framework. Although local NHS services are advised that they ‘ will need to address local inequalities including issues such as access to services for black and ethnic minority communities’ the national targets fail to mention ethnicity. One exception is a national screening programme for

haemoglobinopathy and sickle cell diseases, conditions affecting a small proportion of minority ethnic communities. Initiatives to improve more general access to healthcare services and to address suboptimal care, which are consistently implicated in studies of health inequalities affecting these communities, are framed in relation to socio-economic position and do not specifically target these populations:

‘To underpin this national work on cutting inequalities we will by 2002 develop a new health poverty index that combines data about health status, access to health services, uptake of preventive services and the opportunities to pursue and maintain good health (eg access to affordable nutritious food, physical activity and a safe, clean environment).’ (ibid: paragraph 13.7)

It could be argued that subsuming ethnic group disadvantage within socio-economic disadvantage is a reasonable strategy. For example, Personal Medical Services schemes are designed to improve the distribution of GPs and primary care staff and improve recruitment and retainment of ‘good staff’ in disadvantaged areas, where minority ethnic groups are over represented.

However, the emphasis in these schemes is on geographical siting and no indication is provided within the Plan about the skills needed to develop ‘cultural competence’ or engage with diverse local communities. The historical exclusion of minority ethnic communities from delivery of health and social care suggests that these strategies carry a high risk of failing to adequately address the needs of these groups.

Socio-economic disadvantage is clearly relevant to Pakistani communities, which face multiple disadvantages and discrimination (Modood et al 1997), however, the increased levels of mortality and poorer health within these populations cannot be explained with reference to poverty alone. There is evidence, for example, of significant differences between ethnic groups within the same social class. A better measure of material deprivation, such as standard of living, does go some way to explaining health inequalities. However, ‘controlling for poverty’ does not always eliminate statistically significant differences between ethnic groups. Nor does this approach take account of other aspects of disadvantage such as racism and discrimination (see Nazroo 1997). These features of experience are important in helping to explain why minority ethnic groups are

over-represented in deprived households and more likely to experience worse health as a result.

Whilst acknowledging poor access to healthcare and increased mortality amongst minority ethnic communities, the NHS Plan fails to offer specific strategies to address these problems. A notable exception to this is the NHS Direct translation and interpretation service available from any NHS site by 2003. The influence this will have on access to other services has yet to be evaluated, however this approach appears consistent with traditional constructions of ethnic disadvantage relating primarily to language difference (Robinson 2002).

Reference to ethnic health inequalities is almost wholly confined to a single chapter within the NHS Plan, which fails to inform strategies for improving health covered in other chapters. Even where these inequalities are acknowledged - as in the chapter on old age - initiatives to improve services ignore the priorities of people from minority ethnic communities. Thus, whilst the lack of culturally sensitive services are recognised as causing problems for minority ethnic elders, housing regulations which act against extended family living and the need to develop cultural competence in services (R K Consultancy 1997) do not figure in strategies to improve the health of elderly people. Even in relation to communication skills training, where language and other differences in patient-professional culture clearly affect communication with people from minority ethnic communities, the Plan is entirely silent on training that would equip staff to deal with these issues. Similarly, new resources for increased staffing within the NHS do not highlight the need for recruitment which represents the diversity of local communities using health services.

The consequence of omitting to consider ethnicity at a strategic level has a knock-on effect. For example, the failure in relation to communication skills, highlighted above, means that the methods of achieving patient empowerment - through 'better information, patient advocates and advisors ... [and] patients' surveys and forums' to name a few of the initiatives described in the Plan - is unlikely to have a significant impact within minority ethnic communities.

Thus a focus on health inequalities in minority ethnic groups, despite being acknowledged as a priority within areas such as coronary heart disease, diabetes and mental health, is undermined in two ways. First by an emphasis on socio-economic disadvantage within the

Plan with relatively little reference to ethnicity and, secondly, by exclusion from the majority of strategic initiatives introduced.

The Plan has led to the establishment of a Health Development Agency to address prevention and early detection of ill health, a Healthy Citizens programme and the introduction of Health Improvement Programmes and Health Action Zones for local delivery of information and interventions. These initiatives have not been required to meet specific targets relating to minority ethnic communities, though in practice they may do so. They are consequently likely to show inconsistency and inadequacy in the extent to which they address ethnicity in their work programmes.

Funding available for all the Health Action Zones, which, geographically, include over a third of the population of the UK, constituted less than 1% of NHS resources and included earmarked funds for drugs prevention projects, smoking cessation services, innovation projects and employment and health projects (Bauld and Judge 2002). Evaluations of Health Action Zone (HAZ) activity reveal that these covered a wide range of different projects and activities. The zones were placed in areas where there was a common history of deprivation and poor health. These areas were clearly those of greatest need but also had limited local capacity to develop robust and convincing plans for specific activities that would reduce health inequalities. The zones consequently suffered a 'credibility gap' in relation to their ability to enable the realisation of final health goals (Bauld and Judge 2002).

Community involvement and performance management systems were expected from each HAZ as a means of identifying and addressing local public health needs. However, evaluation procedures - aimed at learning from experience in order to increase the effectiveness and responsiveness of services - were carried out by project managers who were required to evaluate their own work. In the context of short term funding contracts to local projects, this conflict of interest suggests that any expectation that evaluation would not be a bureaucratic exercise but 'of real practical benefit to professionals and service users' (Holden and Downie 2002) may have been unrealistic.

Leeds was the home of the central policy team for HAZ and was funded in the second wave of applications for Health Action Zone status in April 1999. Evaluations of local projects appear to be of questionable quality, not only for the reason given above, but also

because evaluations were often not built or costed into projects, it was unclear to whom evaluation outcomes should be addressed and many project managers lacked experience of carrying them out (ibid). Holden and Downie (2002) report that project planning cycles (which in theory should have included evaluation) were often truncated because of the speed with which they were set up. Consequently, findings about Health Action Zone activities in Leeds were 'not generalisable' because they were not formally carried out and showed no clear link between actions and outcomes (Health Development Agency 2004). Reports from zones in other parts of the UK confirm that ethnicity has not been routinely addressed either in service delivery or evaluation of activities (Bauld and Judge 2002).

This is particularly disappointing as structural change and the setting of local targets is an important element of the NHS Plan. The aim of providing greater accountability for improving health is promoted through joint working and partnerships between statutory and non-Government organizations. A significant number of new structures are described by the Plan and associated policy papers to deliver its objectives. However little reference is made to how representative of local communities such structures must be. It is also unclear how far the agencies set up to develop and spread 'best practice' on a national scale – such as the Modernisation Agency, the Health Development Agency, the Cancer Collaborative and the Primary Care Collaborative – are themselves equipped to understand and engage with issues relating to ethnic inequalities in health.

The National Primary Care Collaborative's report on its first two years' progress (National Primary Care Development Team 2003) celebrates achievements on a national scale in the treatment of coronary heart disease but does not evaluate how far these have reached people from different social groups. A search of the websites for each of these agencies reveals no evidence of joint work to reduce health inequalities in the Pakistani, or any other, minority ethnic community.¹⁰ The NHS Plan promotes the use of 'successful formulae' already operating within these groups. However, the models for service development promoted by these collaboratives give no indication that minority ethnic communities should be treated as a priority area, suggesting that their work will sustain, if not contribute to ethnic inequalities in health. Research evidence presented in earlier chapters suggests that the process of modernization will need to modify traditional

¹⁰ www.hda-online.org.uk and www.modern.nhs.uk

formulae and structures for service delivery if it is to avoid perpetuating discriminatory barriers that currently sustain health inequalities.

Despite claiming to address the areas highlighted by the Acheson Report (1998), the Plan is, therefore, weak at a strategic level in relation to minority ethnic health inequalities and shows poor leadership to the bodies it aims to reform. None of the objectives set out in the annexed Public Service Agreement refer to the needs of minority ethnic groups. The objective of 'fair access', which might be supposed to refer to improved access to health services for those who have traditionally been poorly served, is defined as 'guaranteed access to a primary care professional within 24 hours and to a primary care doctor within 48 hours by 2004.' How far this target is met within Pakistani communities has yet to be measured, however, it is not unreasonable to suppose that minority ethnic communities will be over represented in GP practices which fail to meet this target.¹¹

The overall aim for the Plan is 'to narrow the health gap in childhood and throughout life between socio-economic groups and between the most deprived areas and the rest of the country.' Whilst, in theory, this should indicate targeted strategies to address ethnic inequalities, in practice, as has been demonstrated above, very little of the Plan specifies such action. Consequently, for minority ethnic communities, the Plan sustains the very situation it highlights: 'the inverse care law' where communities in greatest need are least likely to receive the health services that they require (Department of Health 2000).

The above analysis indicates that in terms of specific action to address health inequalities experienced by the Pakistani community the NHS Plan is limited. In relation to ethnicity, the Plan undermines ethnic differences in health by emphasising social class inequalities. Although it recognises a wide definition of health and causes of ill health, the Plan is almost entirely silent about religious discrimination. This issue is considered in more detail below.

3.2 Faith identity and health

Although religious discrimination is recognised in the introduction to the NHS Plan (Department of Health 2000) as a cause of health inequalities, it is not mentioned anywhere else as having an adverse effect on health and wellbeing. The Plan was published in the

¹¹ Feedback from a local conference to launch the findings of this study indicated that this was indeed the case. Individuals from the Pakistani community complained that it could take weeks to obtain an appointment and that patients who spoke limited English were offered a lower standard of service than other patients.

same year as the Race Relations (Amendment) Act 2000 (HMSO 2000a), which establishes a duty to be proactive and to promote racial harmony, but the Act, in any case, does not address religious discrimination.¹² However, the Plan does point to areas of Government activity that could potentially address this kind of discrimination and thus contribute to reducing health inequalities. Specifically, it refers to the National Strategy for Neighbourhood Renewal (Social Exclusion Unit 2001), which addresses the links between health, education, employment and ‘other causes of social exclusion.’

The Government’s definition of social exclusion is ‘a shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown’ (Social Exclusion Unit 2004a). The Social Exclusion Unit aims ‘to reduce social exclusion by producing ‘joined-up solutions to joined-up problems’ (ibid). Along with the Urban White Paper (Department of Environment, Transport and the Regions 2000), this strategy does recognise the importance of involving faith communities in regeneration. However, despite recognising that some social groups are more exposed to social exclusion than others, both the White Paper and the Social Exclusion Unit fail to recognise discrimination against faith communities alongside race discrimination. Targets set to tackle social exclusion therefore exclude faith groups from their focus:

‘Long periods of unemployment and worklessness can lead to poverty, poor health and social isolation. This is a particular problem for those groups who face most difficulty in the labour market, in particular, certain ethnic minority groups, lone parents, older people and those with disabilities. Paid work is a central element of the government’s strategy to tackle social exclusion.’

(Social Exclusion Unit 2004b para 10)

The two ethnic minority groups with highest unemployment levels and poorest health are the Pakistani and Bangladeshi communities (Modood et al 1997). The fact that both these populations are almost wholly Muslim suggests that faith is a further source of discrimination which affects employment, health and social inclusion. This hypothesis is further strengthened by findings that show the profile of Indian Muslims to be closer to

¹² Jewish and Sikh communities are, nevertheless, covered by the Act as they are defined as racial groups. The multicultural nature of Muslim communities precludes such a definition.

these two groups than to the general population of Indians, which would include other faith backgrounds (Nazroo 1997).

The absence of a focus on faith communities is thus of particular concern in this area of policy. Work on regenerating deprived areas, funded through various specific funds¹³ and local structures to develop and co-ordinate delivery of strategies consistently define discrimination on the basis of ethnicity alone without recognising Islamophobia, a now widely accepted phenomenon (Runnymede Trust 1997), as contributing to the disadvantage Muslim communities face. The failure of this current approach to achieve success for all groups or in all geographical areas is, however, acknowledged:

‘These measures have helped bring a significant increase in employment, and in the number of people leaving benefits for work in the last five years. The persistence of a few stubborn areas which still have problems suggests a need to examine why policies that have been successful for most people and places have not been as effective everywhere.’

(Social Exclusion Unit 2004b para 27)

References by the Social Exclusion Unit to faith communities encourage the use of faith organisations as a resource for implementing policy initiatives as part of the process of involving local groups. Faith communities are thus drawn on to promote social policy whilst being neglected in terms of its formulation. The Unit has failed to involve these groups in the process of defining their problems and in finding solutions that might help. A review of the Unit found that:

The Unit should do more to involve both those working at a "grass roots" level and people who themselves might be described as "socially excluded" more closely in their consultations. There should be more direct participation in the processes of issue definition and policy formulation by those most directly affected.

(Social Exclusion Unit 1999 p8 para 3.26)

¹³ Such as the Neighbourhood Renewal Fund, the Community Development Fund and the Phoenix Fund

This approach to faith communities - as a resource for policy implementation rather than as groups that may themselves need the support of social policy - can be identified in other Government publications. For example, the basic principles of engaging with faith communities outlined in a DETR document (Department of Environment, Transport and the Regions 1997) draw similarities between the reasons for involving faith organisations in policy initiatives and reasons for involving voluntary and community organisations. Despite acknowledging that faith-based groups have as much right to be involved in social policy initiatives as voluntary and community organisations, however, the DETR document appears to place particular emphasis on the additional resources such groups can bring to partnerships or programme outcomes, and these resources are promoted as the prime reason for engagement. They are described as often having better resources than other local bodies, in terms of paid staff, premises and access to funds such as special trusts and members' donations. Structures are seen as potentially well-developed both legally and constitutionally and membership of a national network may offer access to further resources.

The potential contribution faith-based organisations can make to social policy implementation is seen as arising largely from the nature of their resources, which are often unique in character. Places of worship, for example, provide good local contacts and links across a wide range of social groups. As the first basis for self-organisation in some communities, faith organisations may be the only ones with significant resources in some neighbourhoods (ibid). Links between faith and ethnicity are also recognised and the role of mosques, gurdwaras and synagogues in representing the views of particular ethnic groups is highlighted. The document suggests that underestimating the importance of faith-based groups is as serious as omitting ethnic minority groups. Despite this, the participation of faith organisations in local activity on neighbourhood renewal and social inclusion is recognised as inadequate. This inconsistency is related to local attitudes towards faith communities and suggests lower acceptance in some areas (Department of the Environment, Transport and the Regions p149):

‘The broad picture is still patchy, with enthusiasm in some areas matched by apparent reluctance to involve faith communities in others.’

(Office of the Deputy Prime Minister 2004 p1)

In relation to attitudes within faith communities themselves, the DETR statement recognises that unwillingness to become active partners in the delivery of social programmes may be linked to tension within and between groups. Other barriers to engagement may arise from lack of familiarity with the processes and frameworks involved or underdeveloped management skills. Again, similarities with other community organisations are highlighted and the importance of their role in neighbourhood renewal and social inclusion re-emphasised.

The focus on justifying the involvement of faith communities suggests that the DETR document is aimed at reluctant policymakers and practitioners rather than at faith communities themselves. Furthermore, despite the evidence that faith organisations in Muslim communities struggle to exist (Geaves 1995), there is an assumption that 'human, material [and] spiritual' resources can be internally sustained without the need for statutory support. This resource contribution, which appears an unlikely expectation from Muslim faith organisations, is promoted as a major reason for including faith communities in the health activity related to the wider determinants of health of such as urban renewal and social inclusion.

3.3 Conclusion

This chapter suggests that social policy on faith and health is extremely underdeveloped and currently behind policies on race equality, which themselves do not move far beyond acknowledging discrimination. Ethnicity is conceptualised as separate and marginal in key policies relating to health and religious communities are perceived as subsets of ethnic groups rather than as primary groupings for self-organisation. Unwillingness to engage with faith communities on equal terms is also apparent from the analysis of policy in this chapter. For Pakistani communities, social policy appears unlikely in either area to stimulate targeted or consistent improvements in healthcare or related areas of service development.

The more developed, though clearly still inadequate, policy stance on ethnicity has been facilitated by data from the 1991 Census, which, for the first time, collected national ethnic statistics. The 2001 Census included an optional question on religious identity and it is likely that this may also be used to influence social policy. The demographic profile of Pakistani Muslim communities is, therefore, explored in the next chapter as another source of information for the relationship between religion, ethnicity and health inequalities.

Chapter 4: The Demographic Profile of Muslims in the UK

Having explored the historical, sociological and policy treatment of religion, and in particular, of Muslim identity, this chapter explores available demographic data about Pakistani Muslims as a further means of understanding the context in which this research took place. Data relating to Pakistani and Muslim groups at a national level and in the fieldwork area is examined. A newly introduced question on religion in the 2001 Census provides the most recent information on the demographic profile of Muslims in the UK. Continued inclusion of a question on ethnicity means that the particular circumstances of the Pakistani population can be explored within this religious group.

The voluntary question on religious identity was answered by 92% of the population and, contrary to the predictions of those working in the Office for National Statistics¹⁴, faith has emerged as a definite aspect of identity for most people in the UK:

Just over three-quarters of the UK population reported having a religion. More than seven out of ten people said that their religion was Christian (72 per cent). After Christianity, Islam was the most common faith with nearly 3 per cent describing their religion as Muslim (1.6 million)
(Office for National Statistics 2004a).

Census figures reveal that the ten largest Muslim communities in the UK form between 12.26 and 36.4 per cent of a city's total population. Comparative figures for the top ten cities in which Hindu, Jewish and Sikh populations live show that these communities constitute between 3.07 and 19.61 per cent of the total population (ibid). Thus Muslim populations, which are drawn from a wide variety of ethnic groups rather than reflecting a single ethnicity, form considerably larger communities in the cities concerned.

These figures do not, of course, offer information about the diversity of experience and practice within and between faith groups. However, factors relating to social class and

¹⁴ At a conference on 'The Demographic Profile of Britain's Muslim Community' a spokesperson from the Office for National Statistics stated that she expected most people would state they had no religion

lifestyle patterns do emerge from Census data. For the first time in the UK, social class categories are available by religious and ethnic group, although analysis by the Office for National Statistics does not always use both categories. Figures for the one million Pakistani and Bangladeshi people in the UK (who as the two largest Muslim populations have previously been used as a proxy for Muslim communities) reveal that sixty-eight per cent live in low-income households compared to twenty-one per cent of white households. The hypothesis that this disadvantage is related to faith background is confirmed by the local data on religion and socio-economic position in Appendix 2 and this is described in more detail below.

4.1 Religion and socio-economic position

The figures and chart in Appendix 2 provide a breakdown of the socio-economic position of different religious groups in Leeds, where fieldwork for the study took place. Membership of the Muslim community is more than double any other minority religious group in the city yet the numbers of Muslim people in higher social class categories is similar to the Jewish or Hindu communities, whose populations are far smaller (approximately 5/12ths and 1/4 as large respectively. In percentage terms, Muslim representation in higher socio-economic groups is lower than any other faith community (see Appendix 2, Chart 1).

Census data also reveals noteworthy information about the areas of Leeds in which this study was based - Harehills, Chapel Allerton and Moortown. Although the Pakistani and Muslim communities (respectively 2.11% and 3% of the Leeds population) were both higher than the Leeds average in all three areas¹⁵, within Harehills, one of the most deprived wards in the UK (Office for National Statistics 2004), 25.7% of the population was Muslim and 18.7% Pakistani (ibid). These figures show that Pakistani and Muslim communities are over represented in the most deprived area of the city and that within certain geographical areas, the significance of these communities is clearly far greater than across the city as a whole.

Census data also reveals higher unemployment levels resulting in less economic activity and suggesting that more time is spent at home by people within this community. This

¹⁵ see Appendix 2

suggestion is reinforced by national data showing an apparently strong culture of women staying at home to look after their families:

‘A high proportion of Pakistani and Bangladeshi women aged 16-74 look after the home and family - 36.4 per cent of Pakistani women and 40.1 per cent of Bangladeshi women, compared to the average of 11.9 per cent for England and Wales.’

(British Council 2004)

This aspect of lifestyle may be partly explained by the fact that Muslim populations have a very high proportion of young people – more than half of Muslims are aged 24 and under (ibid). However, similarities between Pakistani and Bangladeshi women in terms of work patterns, and differences with other South Asian groups who have similar proportions of young people, suggests that faith values, rather than, or in addition to ethnicity, may be an influence on women’s choices. If this is the case, then the influence of faith on choices in other areas of decision-making, including health, should be expected.

Apart from choices based on faith values, however, the data suggests that religious discrimination may be a further factor in these higher levels of unemployment. Even if all Muslim women chose voluntarily not to work, this would still not result in unemployment levels that are at least four times higher than in any other religious group.

The relevance of faith to lifestyle and wellbeing is further suggested by findings from the 2001 Census data that children from Muslim households are more likely to live in ‘workless households’, to live in overcrowded accommodation and in houses without central heating (Office for National Statistics 2004b). Current choices by the Office for National Statistics, however, mean that their own analyses may be carried out using ethnic rather than faith categories. Similarities and differences across faith groups may consequently not be highlighted (Muslim Council of Britain 2002a; Forum Against Racism and Islamophobia 2002). Census figures confirm previous evidence of higher rates of poor health among Pakistani people (Nazroo 1997), however, detailed analysis of the relationship between religion and health has not yet been carried out across or within religious groups.

Using Pakistani and Bangladeshi communities as a proxy for Muslims in the UK confirms that social policy initiatives to address health inequalities amongst minority ethnic

communities (considered in the previous chapter) may have less impact on Muslim communities than on other minority groups. For example, among men aged 50-64 and with a limiting long-term illness, the proportion of Pakistani men reporting their health as 'not good' is almost double the national average and higher than other minority ethnic communities. Findings for Bangladeshi people present a similar profile, again suggesting that the common faith between these groups may be a reason why they are particularly disadvantaged in relation to other ethnic minorities. As already highlighted, the influence of faith on health and wellbeing has not been well researched in the Pakistani community. Evidence highlighted in this section suggests that research into the relationship between religious identity and disadvantage could help explain the health inequalities people that people within the Pakistani and Bangladeshi communities experience.

The national picture has been considered alongside local information in this section. This is important because differences between the socio-economic and other profiles of Muslim communities have been found between geographical areas (Anwar 2003). A more detailed picture of Pakistani Muslims in Leeds and in the fieldwork area is valuable for this reason and is, therefore, explored in the following section.

4.2 The local picture

Analysis of Census 2001 figures for Leeds show that the city has the largest minority ethnic population of the eight local authorities in Yorkshire and Humberside (The Leeds Initiative 2004). The proportion of minority ethnic groups in Leeds has almost doubled since the last census to 10.84% of the total population.

Muslim identity automatically suggests association with other ethnic groups, such as Bangladeshi and Arab communities, in which Islam is the dominant religion. Muslims who form a minority in some ethnic groups, for example in Indian, white and African or Caribbean communities, are also revealed in the process of establishing faith identity. This potentially increases the perceived significance of Muslims as a social group. Thus, the 15,064 Pakistani people in Leeds form 2.11% of the total population in Leeds. As part of the Muslim faith community, however, they form 3% of the Leeds population – a similar proportion to that of Muslims nationally. People from Pakistan form 19.42% of minority ethnic communities in the city, whereas Muslims form 26.7% of these same communities (The Leeds Initiative 2004).

As this is the first time that data about Muslims has been collected through the Census, it is not possible to compare all these figures with previous data. However, Census figures for 1981 and 1991 show that the Pakistani population almost doubled during this period, mirroring the current increase in the city's minority ethnic communities. As a proportion of the South Asian population, this community's position has increased slightly - 46.7% (The Leeds Initiative 2004) now as compared to 44% in 1991 (Geaves 1995). The 1991 Census showed that slightly less than half of Pakistani people lived in the inner city Harehills ward with about an eighth living in the more affluent Moortown area. Figures from the 2001 census show that this figure has changed dramatically and slightly less than a quarter of Pakistani people now live in Harehills. Figures for Moortown confirm previous observation of the suburbanisation of the Pakistani community away from inner cities (ibid).

Geaves' (1995) study of Pakistani people in Leeds provides additional information on local changes in demography and on community organisation. He describes the dominant Pakistani group in the city as the Mirpuri group, although this description shows some of the confusion between religious and ethnic identity discussed in Chapter 2.¹⁶ His description of early settlement patterns demonstrate that the family was the backbone of social support within this community.

The study also provides evidence of difficulties in self-organisation around faith. The voluntary nature of faith activity in the Leeds Muslim community had the consequence of slow progress for organised faith groups and of poor leadership within the faith community. Geaves suggests that self-employment and consequent lack of free time was a reason why Muslims in Leeds were poorly organised. His account indicates the absence of paid work to promote social networks based on faith and the lack of external support for this kind of self-organisation (a policy position noted earlier in Chapter 3). All mosques in the city were self-funded by this community, initially through joint efforts between the Pakistani and Bangladeshi communities and later, as numbers grew, by the different ethnic communities separately. Leadership by mosque committees showed little activity, however, apart from buying premises. Even this level of activity was difficult to maintain: between

¹⁶ He refers to 'Kashmiris' (an alternative and now more popular description of people from the Mirpur region) using a particular mosque, although it is clear from his study that people from this region also attend other mosques in the city.

1980 and 1991 all of the city's mosques were under pressure for space, particularly on Fridays or during religious holidays (Geaves 1995).

Religious practice in Leeds appears to have been similarly underdeveloped. A number of respondents in the research sample described such practices as 'rites of passage' rather than a 'central factor of life'. Geaves points to lack of formal education and literacy as the reasons for his respondents' unsophisticated knowledge of their own faith, which was often learned from 'wandering religious teachers' who taught by rote¹⁷. Geaves found no evidence of Islamic youth groups in Leeds except in the Universities. A possible explanation for this is that such groups were meeting in people's homes and not affiliated to mosques. They could also be led by Muslims from other ethnic communities and their organisation may have been unknown to Pakistani individuals active in mosque committees.¹⁸

4.3 Conclusion

Exploration of the demographic profile of Pakistani Muslims reveals that this community forms a significant part of both the minority ethnic population and of the Muslim population both in Leeds and the UK. Evidence appears to confirm the need for research that can inform social policy in relation to this community, as suggested in Chapter 3. I have examined the reasons why such evidence may be underdeveloped in earlier chapters, but resistance to acknowledging or valuing faith identity has been a recurrent theme in this review. This analysis of the literature suggests that although religion cannot replace ethnicity (or for that matter social class, age and gender) as a way of defining Pakistani communities, it can contribute to a more complete picture of their experience. As such, religion provides an alternative means of identification that may at times be more appropriate than other frameworks to understanding health inequalities within this community.

Chapters in this review of literature suggest a relationship between Muslim identity and disadvantage that is confirmed by the most recent national data from Census 2001. It thus

¹⁷ The limited number of respondents in Geaves study and his own position as an outsider to the Pakistani Muslim community inevitably means that this description of religious practice is far from comprehensive. However, it provides useful information in relation to individuals involved in the Leeds mosques at the time of the study and their contribution to the development of religious practice in Leeds.

¹⁸ My own experience as a member of the Leeds Muslim community points to the existence of at least one Young Muslim girls' group active in Leeds during the period of Geaves' study.

indicates an area where research may help to explain why policies that have focussed on ethnicity have not been as effective in overcoming disadvantage within the Pakistani Muslim community as in some other communities. The context provided by this literature review constitutes an important background in which to understand findings from this study. The following chapter outlines the methods used to collect and analyse data and the impact this had on the kind of data collected.

PART II: METHODOLOGY

Chapter 5: Lived Experience, Social Life and Social Commentary

5.1 Introduction

This chapter aims to make explicit the process by which I formulated my research questions, the methods I used to investigate them and analyse data, and the ideas or assumptions that shaped the research. My own study was built into, and used data from, another project on chronic illness within the Pakistani community, for which I was the lead researcher (henceforth, 'the communication project').

The communication project aimed to explore how Pakistani people with chronic illness gathered information and knowledge of their condition over time and how they made use of it to manage their condition. Research questions were particularly concerned with how community networks contributed to the self-care of people with chronic illness and the way individuals within the community interact, share and evaluate information about chronic illness management. The project also aimed to investigate interactions between different stakeholder groups in order to identify differences and similarities in their perceptions that might affect the management of chronic illness.

Research questions for the communication project used the theoretical framework of ethnicity to explore the research questions, although other aspects of identity were taken into account. Having been involved for a number of years in research on ethnicity and health, I was increasingly dissatisfied with the incompleteness of this framework for understanding members of the Pakistani community, given the primacy of religious identity within it. I felt the opportunity to explore this theme in far more detail, rather than the brief focus often accorded to religion in studies on ethnicity and health, was important. In my analysis of the data for this thesis I focused, therefore, on questions that were significantly different to those posed by the communication project. These have been outlined in the Introduction to this thesis, namely:

- How does communication between different stakeholders affect chronic illness management and what is the influence of religious identity on this process?

- What are the different factors that affect patient¹⁹ decision-making in relation to health and how influential are religious beliefs?
- What impact does Muslim identity have on the lives of Pakistani people in the fieldwork area and what does this tell us about inequalities in healthcare and inequalities in health?

My focus on religious identity meant that the literature review had to be almost completely rewritten and data revisited and explored from a different perspective and in far more detail. In addition, the wider literature on health inequalities, which was not explored in detail in the communication project is also addressed in this thesis (see Chapter 9).

The processes of communication and decision-making offered rich opportunities to gather evidence about the influence of religious identity that would have practical implications for policy and practice. I was especially interested in these outcomes because of their relationship to empowering research subjects (Barnes 1996). This issue is discussed further in the section on Ethical Issues, later in this chapter.

The following sections outline why research methods were chosen and how data sources were selected and used. The way in which data was collected and analysed and the advantages and limitations of this approach are also explained and discussed. My attempts to be reflexive throughout the research process are highlighted in each section, however, the aims of this reflexive approach are discussed towards the end of the chapter.

5.2 Choosing the research methods

The design of this study was, to some extent, already determined before I began work on my thesis, having been set out in the proposal for the communication study. However, I developed and made concrete the research team's broad ideas about the methods that should be used and I used additional data sources to those used for the communication study in order to address my own research questions, which were significantly different.

The original research design was based on the premise that a qualitative approach is particularly effective when an area is under-researched, complex relationships are involved,

¹⁹ This term is used to differentiate people in different respondent groups, whilst recognising that people with chronic illness are 'patients' for very little of their time.

and when the life experience of participants is crucial to the development of knowledge (Bryman and Burgess 1994). Broadly-based ethnographic work was proposed to gain an understanding of how the Pakistani community operated on a day-to-day basis, to identify important social and cultural networks and to achieve an understanding of the ways in which members interacted and shared information. Hammersley and Atkinson (1995) give an account of ethnographic traditions based on the principle of 'verstehen'. Detailed accounts of the concrete experience of life within a particular culture are used to discover and understand the beliefs and social rules that are used as resources within it. Social processes are therefore observed in their natural settings and the meanings that guide behaviour are made explicit.

A research design which produces as many categories and properties of categories as possible is recommended as most appropriate for the elaboration of theory in a particular area of research. It is suggested that these categories should be identified both by the researcher and by those being observed. Sampling within a group allows the relationships between, for example, socio-economic background, age or level of formal education and other themes to be identified and theory to be tested. Ethnographic fieldwork combines observation, informal 'interviews' and in-depth case studies as a powerful means of investigating complex questions relating to experiences and relationships (Hammersley and Atkinson 1995).

Ethnographic contributions to the literature on chronic illness and healthcare have added evidence of a specific kind. They have not only enabled a deeper understanding of the views and actions of individuals but have also captured the social complexity of their lives (Charmaz and Olesen 1997). Studies have highlighted the ability of this methodology to aid understanding of social processes (Hammersley and Atkinson 1995) and identify variations in patients' perspectives and needs over time (Lewis et al 1997).

Ethnographic methodology recognises the social context of an individual's life and the fact that people are patients for very little of their illness experience. The majority of their time is spent in their own families, communities and environments rather than in medical settings. The perceptions of significant others and the personal and social circumstances within which individuals live are crucial to understanding communication patterns and decision-making processes (Donovan and Blake 1992). Professionals as well as patients are affected by their social context, though both may be unaware of the constraints and

power relationships rooted in their interactions with others (Charmaz and Olesen 1997). Attention to such dynamics has highlighted that different sites of data gathering can demonstrate a different layering of power relations (Dyck 1995). Ethnographic methodology can also reveal significant differences in the values and beliefs of people with chronic illness, carers and professionals (Charmaz and Olesen 1997), understanding of which is vital to developing effective care interventions (Rybarczyk et al 1999).

The changing nature of many chronic conditions is a reason for including a temporal aspect to research in this area. At times of critical illness, for example, forms of communication involving collaboration or negotiation with physicians and full disclosure of information may be of minimal relevance to patients (Rier 2000). When individuals have come to terms with the shock of a critical event, however, they may lose their trust in, and question, official accounts of cause and recovery (Wiles 1998). Furthermore, people with chronic illness go through varying stages in terms of making the behavioural changes recommended by professionals (Lewis et al 1997). There is also evidence that distinguishing between minority ethnic patients' experience and perception of services at different stages of their illness course might indicate at which point difficulties arise in terms of their interaction with health services (Hutchinson and Gilvarry 1998).

The 16 months allocated for ethnographic fieldwork was insufficient to demonstrate significant changes in the way respondents from each group interacted with each other. Temporal aspects revealed as most significant in this period related to the impact on chronic illness management of particular events – such as fasting during Ramadan²⁰ or travelling abroad. At a wider level, the panic in community organisations in the months leading up to a new financial year was also a significant time-related finding that emphasised the insecurity of these groups. The ability to follow people over a period of time rather than gaining a single 'snapshot' of their views was helpful and enabled me to gain a deeper understanding of respondents' views and the relationships they had with family and community members and with healthcare professionals. An ethnographic approach also enabled me to understand their experiences in relation to relevant processes and contexts.

²⁰ See Glossary: Appendix 1

5.3 Approach to fieldwork

As already highlighted, a range of possibilities existed about when and where to observe or converse with people from stakeholder groups in the fieldwork area. The initial strategy was to maximise the range of both times and settings for fieldwork so that these could be taken into account when analysing the data. In theory, I was to become 'immersed' in the everyday life of the community rather than making short visits. In practice this ideal was not always achievable.

The fieldwork area had originally been conceptualised to cover Leeds and Bradford. However, it quickly became apparent that the depth of understanding needed about community networks could not be achieved over such a wide range and without some existing knowledge of these networks. The geographical area on which the research focused was therefore narrowed down to 2 miles around the Harehills area of Leeds. This included Pakistani people who lived in the areas of Moortown, Chapeltown, Chapel Allerton and Roundhay, where Pakistani community networks were yet to be established and who, therefore also used the same networks as those living in Harehills.

I was assisted during fieldwork by a Pakistani male researcher, who spoke one of the languages used within the Pakistani community in addition to English. Language and gender considerations were vital to gaining access to relevant settings and networks. Between us, we spoke or understood Urdu, Punjabi and Mirpuri dialect. My own established community links were of paramount importance at this stage, as they facilitated my own and my colleague's initial access into important community networks.

I began by contacting people in Pakistani community groups in order to arrange visits to observe what they were doing and talk informally about their work. I focused initially on an 'Asian women's group' that was in fact almost exclusively made up of Pakistani women and that focused on health promotion activities. The group facilitator, who was also Pakistani, had organised a regular exercise session and invited weekly speakers as well as arranging trips. I began by interviewing her as a 'key informant' (see Data Sources below) and then asked about getting involved in the group. I and my colleague gradually increased the number of groups we became involved with over the following months.

From my previous experience of research within this community²¹ I was very aware of cynicism about benefits to the community from research carried out within it. Consequently, I was prepared to build in an element of reciprocity rather than be a drain on the resources of individuals and groups. The facilitator of the Asian Women's Group had already mentioned the difficulty she experienced in running the group without any support. I volunteered to help her run the group and she was very keen for me to be involved in this capacity. She validated my approach a number of times during the 12 weeks in which I took part in the group, contrasting it with other research projects and consultation exercises. These had expected her to organise women to be interviewed or consulted on top of everything else for which she was responsible without offering any extra resources. Although this way of becoming involved in the group meant that I assumed a particular position within it, I felt it avoided exploiting the group facilitator and allowed my role as a researcher and volunteer to be explicitly introduced to group members.

Through fieldwork, I attempted to achieve an understanding of the beliefs and social rules that were used as resources for health and for chronic illness management within the Pakistani community. Various forms of participation were possible: ethnographic methods have ranged from correspondence with research participants (Kralik et al 2000) to covert observation of particular social groups (Charmaz and Olesen 1997). A covert approach to research may allow the study of features that would otherwise be inaccessible (ibid). However, a known researcher role is recommended as allowing optimum data collection (Hammersley and Atkinson 1995; Harvey 1990) and I felt that this would be more acceptable to respondents. This acceptability is an important criteria in good practice guidelines on health research (Ryan et al 2001).

The role adopted by the researcher can also vary in terms of the level of involvement with people included in the fieldwork sample. 'Complete participant' and 'participant observer' roles include interaction with those being observed and are less detached than the roles of 'observer as participant' and 'complete observer' (Hammersley and Atkinson 1995 p104).

²¹ I had carried out fieldwork interviews with many Pakistani respondents for projects on thalassaemia, caring, mental health, deafness, learning disability and measures of socio-economic position. I had also recently completed a study on cerebral palsy in which respondents had been predominantly Pakistani (Mir and Tovey 2003)

However, both complete detachment and complete participation may place severe limits on questioning and observation although they may be unavoidable and useful at times.

In practice, it was not always possible to choose the role I adopted because of the nature of the setting and reactions of others. For example, in a study circle setting I could simply listen and observe without any problems, as did many other people in the group but asking questions was limited by the fact that the group operated as a class. In other groups participation was expected but adopting too obvious a research role could be disconcerting to members. Reflexivity was important to making decisions about the most appropriate role to take. Shifts between roles are recommended to discount the effect of a particular stance on the data (ibid) and this was the most practical approach, which I adopted during fieldwork.

Validation of this approach to fieldwork was sought at various times during the research process and from various stakeholders. The three Advisory Groups set up for the communication project were an important source of validation and these are described in more detail below.

5.4 Advisory group

The brief for the communication study involved setting up an Advisory Group, which included community representatives, professionals and policy makers. Meetings were held at six-monthly intervals and advice was sought on all aspects of the research. I ensured that the group had a good representation of individuals who would have regular contact with Pakistani people with chronic illness, such as staff in community organisations, interpreting services and people employed to address inequalities in healthcare or service user inclusion. In addition to general advice, members of the Advisory Group helped facilitate access to community networks, helped ensure that the work retained practice and policy relevance and advised on dissemination to respondents and professionals.

The group was made up exclusively of professionals, none of whom had personal experience of chronic illness. The feasibility of involving service users on this group was doubtful, given that it was run in English and that much of what was discussed could have been daunting to someone unused to research. I decided to establish two Users Advisory Groups separately and to use the expertise of these members to develop fieldwork tools and to help validate findings. As community-based groups were mostly gendered, separate

men's and women's groups were established. The groups were made up of volunteers²² from a local community organisation included in the study. Members met to discuss and comment on a selection of questions from the topic guide for people with chronic illness that had been developed for the first round of interviews. A further meeting of the Users Advisory Group helped validate initial findings and pilot the participatory methods used in third interviews (see Data Collection below).

5.5 Data sources

I chose a variety of data sources for the study, which extended beyond those envisaged for the communication project (see Table 1 below). The data gathered from these sources allowed exploration of how religion influenced wellbeing at three different levels, in line with the model described in the Introduction to this thesis. The patient, carer and professional interviews throw light on the impact of religion and its effect on chronic illness management at a personal level. Community fieldwork and the views of community-based professionals helped me to explore the dynamics of religion in the Pakistani community as a whole and revealed shared understandings at a community level, which could validate and extend findings from individual interviews. Data gathered from national and international sources allowed me to examine how far the self-perception of Pakistani community members reflected the way Muslims in general see themselves, and how they feel others perceive them. This third level data is often a commentary on Islam and Muslims and sources were particularly active in response to national or global events that were perceived as a threat to Muslims generally (see Chapter 8).

Within all three types of data there was overlap – individuals with chronic illness could comment on the state of Muslims in the world, whilst information on the internet could narrate the experience of a single person in Palestine. Nevertheless, the richness of the data as a whole enables this thesis to provide a multi-level account of the experience of individuals with chronic illness in the context of their wider social experience – within their families, their local community, UK society and in terms of international events.

The diverse data sources helped me to build a detailed picture of the context in which chronic illness was managed and the influence of religious identity within this, whilst taking account of other belief frameworks that operated at an individual and community level.

²² Participation was voluntary but group members were paid for their contribution in line with guidelines on involving service users in research (INVOLVE 2004)

Data sources used to build up this complex picture are detailed in the table below and further details about each source is given in the paragraphs which follow:

Source of data	Details
Interviews with key informants	13 semi-structured interviews between October and December 2000
Community-based ethnographic work	Between January 2001 and May 2003 (see Table 2)
Interviews and contacts with adults recently diagnosed with chronic illness	1-3 semi-structured interviews with 31 respondents and informal contacts over 12-16 months
Interviews with carers/family members	11 semi-structured interviews
Professional interviews and 'shadowing' of appropriate professionals in both practice and community settings	10 semi-structured interviews and 12 observations of healthcare settings (see below)
Messages from local, national and international email groups set up for and by Muslims	11 groups with varying levels of mail followed over the fieldwork period
Local information and policy relating to health facilities, ethnicity or the Pakistani community	Documents collected over the period of the study and attendance at related local events.

Table 1: Types of data source

5.5.1 Key Informants

Thirteen interviews were conducted with 'key informants'. In the first phase of fieldwork, individuals with relevant experience were drawn from a range of stakeholder groups such as GPs and other healthcare staff, liaison officers, interpreters, racial equality council officers and community members. They gave direction on the kind of issues that would be significant to chronic illness management in the Pakistani community and community networks that could relate to health seeking behaviour. Themes arising from the key informant interviews were used along with themes from the literature review and from community-based fieldwork to develop a topic guide for use in the first phase of patient interviews.

5.5.2 Community organisations and groups

Thirteen community organisations were included as data sources in order to gain an understanding of how community networks operated in relation to health. In addition I collected information and literature about a range of other groups within the fieldwork area

to gain an overview of how Pakistani community networks fit into the wider network of community activity. The groups involved in the study and the way in which I and my colleague became involved in each group are described in the table below:

Type of Group	Details of involvement	Period of involvement
Asian women's group	Volunteering, taking part in trips and events	January 2001- April 2001
Asian women's healthy eating group	Occasional attendance at weekly meetings	April - May 2003 ²³
Asian women's elderly group+	Attending as group member/researcher, taking part in informal discussions	January 2001 – February 2003
Muslim women's study circle	Attending weekly/fortnightly as group member/researcher	January 2001 – December 2002
3 local organisations (housing, health promotion and advocacy)	Informal contact with workers in the organisation. Referral and follow up of people with chronic illness who needed advice, support with benefits or advocacy	January 2001 – April 2003
Support group for hospital based Asian worker employed to improve access for Asian women	Fortnightly/monthly meetings; involved in drama production highlighting difficulties of Asian women using maternity care	January 2001 – September 2001
Pakistani men's elderly group 1*	Volunteering weekly and taking part in activities/informal discussions	January 2001 – May 2001
Pakistani men's elderly group 2*+	Attending occasionally and taking part in activities/ informal discussions	January 2001 – May 2001
AGMs, consultation events, open days held by community organisation	Attending one-off events	January 2001 – February 2003
Leeds Muslim Forum	Regular attendance at fortnightly/monthly meetings. Participation in e-list for members and events/demonstrations/training organised by group members	October 2001 – June 2003
Two mosques	Attended Friday prayers occasionally and listened to sermons	January 2001 – February 2003

Table 2: Community groups

* data for these groups was collected by my male colleague

+ members of the two Users Advisory Groups were drawn from these groups. Despite its title there was a varied age range within the group.

²³ This was a short term group set up towards the end of the fieldwork period

5.5.3 Pakistani people with chronic illness

Qualitative interviews were carried out with 31 Pakistani people who had been diagnosed with a chronic illness in the last year. Twenty-two of these individuals were interviewed a second time six months later and 20 a third time, a year to 16 months after their original interview. Semi structured interviews were carried out in the first two interviews. A different approach using more participatory methods was added in the third round of interviews to assess the impact of a different method on communication between researchers and respondents (see Data Sources below).

Some respondents expressed their appreciation of the research project and felt it would be of benefit. They had their own ideas of the underlying problems in relation to chronic illness management which they were keen to let us know:

‘The running around that you’re doing, the effort you’re making, it’s good. People are benefiting from it quite a lot, but the main thing, the foundation is the same. Like I said before, the language problem is the biggest problem. Until that is properly sorted out, you can’t get proper treatment or anything else. This is a big problem. That’s the main thing, the language.’

(NB - male with coronary heart disease)

Informal contact with people in the patient sample was also an important source of data for this respondent group (see Case Studies below). Table 3 overleaf gives background details for the people with chronic illness included in this study

5.5.4 Carers

People with chronic illness were asked to identify a person who was most involved in supporting them to gain information and make decisions about their health. One individual identified two people within the family and eleven carers in total were interviewed. The majority of people with chronic illness lived with their family, although there were some exceptions, and most carers lived in the same household. Most carers were female; either a spouse or a daughter was most commonly identified as the main carer.

Where informal contact was maintained with individuals in between the three interviews, these and other family members also interacted with me as well as with my colleague. In this case, and with their permission, their views and actions were also documented as a

complementary method of data collection. Carer interviews helped me to understand family dynamics in relation to chronic illness management, the kind and quality of support available to individual people with chronic illness and similarities and differences between carer and patient perspectives (see Appendix 4).

5.5.6 Health professionals

I made an effort to include health professionals from various health services related to chronic illness in Leeds and to gain a cross section of primary and secondary care and hospital and community-based services. I undertook detailed observations of interactions between professionals and patients in the following contexts:

- A diabetes clinic (observation of patient pathways and of the work of a doctor, specialist nurse, dietician and chiropodist; semi-structured interviews with two specialist nurses and a consultant)
- A cardiology unit (semi-structured interview with a consultant)
- An oncology unit (semi-structured interview with a consultant responsible for communication skills training)
- A hospital mental health unit (semi-structured interview with a consultant psychiatrist)
- Two community health clinics (observation and informal discussions with GPs, interpreters and community health visitors)

Ten people with chronic illness gave consent for me to interview a professional who had an influence on their health behaviour and decisions. Most people suggested their GP, however, two hospital consultants and one community health worker were also put forward. These semi-structured interviews, along with the observations and shadowing activities outlined above, gave valuable insights into the perspectives of professionals, not just in relation to the healthcare of Pakistani people with chronic illness as a whole but also into their relationships with individual patients.

5.5.7 E-lists

Local, national and international events relating to Pakistani and Muslim populations that were reported in the media formed an important backdrop to the study. Over the three year period in which the research was conducted, disturbances in Harehills and the terrorist attack in New York in 2001 had a particular impact on the Pakistani community in the fieldwork area. The significance of these events and the way in which they were

interpreted was discussed both within community settings but also through e-lists organised by Muslim groups at local, national and international levels.

These groups, which required a high level of literacy in English, were made up of people who were, in some ways, significantly different to the majority of people within the patient sample. However, comparison of the data from these lists with that from community-based ethnography and patient interviews highlighted similarities in the way Muslims interpreted such issues. At the same time, use of these different data sources also allowed exploration of social class and ethnic diversity in the way people responded to these events.

The media was highlighted as a major theme by participants in these e-lists: newspaper reports and television programmes were often criticised or praised and members of lists were urged to complain or write in support to media channels and to watch or call for the banning of particular programmes. The way in which these events and reports about Muslims were presented in the media was often seen as an indication, by respondents in the fieldwork area as well as by e-list participants, of the social position Pakistani people, or Muslims generally, held in the UK.

5.6 Sampling and selection

The research design for the communication project envisaged, first, identification of a selection of knowledgeable professionals and active members of the Pakistani community (key informants) to guide the initial phase of the project. In this first phase, I also needed to select community groups and organisations that would help me understand the networks within the Pakistani community that were relevant to health and to faith organisation. Following this, 25-30 Pakistani people with a recently diagnosed chronic condition had to be identified for the patient sample. The study design involved triangulation, that is, incorporating data from a variety of perspectives in order to gain a more sophisticated understanding than could be achieved from one point of view (Denzin 1989). For half of this sample, therefore, I sought consent to interview carers and influential professionals as a way of enhancing the validity of findings.

As highlighted earlier, I was also concerned that settings should include a variety of contexts – community-based and secondary care sites as well as public and private places. Gaining access to these sites could involve contact with ‘gatekeepers’ and persuading them

to support the research (Hammersley and Atkinson 1995). The means by which people from each respondent group were selected and identified are outlined below.

5.6.1 Interviews with key informants

As already mentioned, the original fieldwork area comprised Leeds and Bradford. Problems with trying to attempt ethnographic data collection over such a large area only became apparent when I attempted to map community organisations and realised that I would only be able to achieve a superficial understanding of community structures unless the fieldwork area was reduced. Key informant interviews took place before this realisation and so respondents in this group came from both cities. This was not a major problem in terms of identifying key themes as these were common across both areas.

Individuals included as key informants were either suggested by members of the communication project team, who had their own contacts with appropriate people, or recommended by key informants themselves. A number of people in this sample group were also involved in the ethnographic fieldwork. This was helpful because they had a clearer idea of what questions the research was trying to address and so could initiate contact and offer relevant information which they came across, of their own accord.

5.6.2 Community organisations and groups

I selected groups to include in the research (see Table 2 above) because of a link to health or else to faith. Most groups were not directly related to health or chronic illness as few community groups operated on this basis. However, “elderly” groups tended to be made up of people with chronic illness and were not confined to elderly people.

Access to community groups often relied on gatekeepers or sponsors who could facilitate involvement. My existing knowledge of groups and key individuals, my previous work in the area and my bilingual skills were all assets in this respect. However, the pressure under which people worked was often apparent and another reason for being careful not to take up too much of an organisation’s or individual’s time (see Approach to Fieldwork).

As an understanding of the field was gradually achieved and I became more familiar with community networks and functioning, I focused on a smaller number of groups. In contrast with the original aims of the research design, it was not possible to keep a specific focus on ‘communication and information networks in relation to health, illness and health

seeking behaviour'. Fieldwork revealed that very few people used community-based groups in their explicit health-seeking behaviour (see Chapter 7). *Biraderi*²⁴ networks, to which we had not negotiated access, and which could extend across the UK and to Pakistan, were of far greater significance to the social networks of most respondents than community organisations (see Chapter 6). Fieldwork also revealed that these networks were not particularly influential in relation to decision-making about health (see Chapter 7). Data from community networks, therefore, was used during analysis for this thesis to inform findings about the shared understandings that existed within the Pakistani community in areas relevant to the research questions.

5.6.3 People with chronic illness

In theory, the intention was to select purposively for this sample in order to address the research questions for the communication project. This was intended to allow exploration of gender, social class, age, family formation and community networks as potentially important variables in relation to communication and gathering information about chronic illness. In practice, being able to identify 31 Pakistani individuals with a recently diagnosed chronic condition within the limited fieldwork area was so difficult that differences in the above variables were based on chance rather than deliberate selection.

Fortunately, the final gender balance did prove even and there was a good age range of between 18 and 71 years old. Moortown and Chapel Allerton are far more affluent areas than Harehills and Roundhay and so a mix of social class backgrounds was also apparent in the final sample. Information about diversity in family formation and community networks also emerged from the data that was collected from people with chronic illness and carers. All except two individuals were born abroad and had lived in the United Kingdom for between 12 and 43 years. All people in this sample lived within a two-mile radius, which constituted the fieldwork area.

I included in the sample respondents who identified with and formed part of the social networks within the Pakistani community, even though they were born in India, East Africa or the UK. Their inclusion reflected the geographical and historical diversity that a single Pakistani community may contain (see Chapter 8).

²⁴ see Glossary: Appendix 1

I targeted different types of chronic condition in order to explore issues that were common to different conditions and those which were unique to a particular illness. In my letters to GPs and secondary care clinics I asked for help in identifying patients with conditions that are particularly significant for the Pakistani population (coronary heart disease, diabetes and depression).

A decision had been made within the communication project to focus on individuals with a recent diagnosis - within the last three months - rather than those with longstanding experience of chronic illness. This was to allow exploration of communication patterns and decision-making early on in the process of chronic illness management, when it was believed foundations would be laid for long-term self-care regimes. It soon became clear, however, that finding 31 respondents so early after diagnosis was unrealistic. Most people known to people in community organisations had longstanding conditions.

Only two of all the GP practices in the area was willing to commit the time and resources to help in obtaining the sample. Given that only a tiny fraction of their practice population would fall into the category of Pakistani people diagnosed with a chronic illness within the last three months, the communication project research team agreed to my suggestion to extend this period to within one year of diagnosis. Consequently, four patients were identified through primary care, ten through community contacts (including referrals by people already in the sample) and seventeen through secondary care clinics for diabetes and cardiac conditions.

Overall there were 16 men and 15 women in the original sample. Seven patients had a heart condition (6 men and 1 woman), ten had diabetes (6 men and 4 women), five had been diagnosed with depression (1 man and 4 women), four had hypertension (all women) and five had other conditions (3 men and 2 women). In this final group, one person had asthma, one had partial paralysis and the other three were awaiting diagnosis. The communication study team decided to include individuals who were still seeking a diagnosis in order to understand the dynamics of communication during this process. These people had been identified from community sources; three individuals described chest pains, a lump and severe stomach pains; one of these was later diagnosed with cancer. A significant number of people in the patient sample had multiple chronic illnesses; some of which were long standing. Of the original sample of 31, eleven men and nine women continued to form the final patient sample 16 months later.

TABLE 3: Breakdown of sample – Pakistani people with chronic illness

Interviewed 3 times =20 people (9 men/11 women). Interviewed less than 3 times = 11 (Underlined) People who requested follow up =10 (bold)

Gender	Condition/diagnosis					
	Heart condition	Diabetes	Depression	Hypertension	Other	
Male	Re- interviewed 3/6 male 0/1 female NB – 71 NC - 45 CT - 49 BB – 44 [gets too upset] NT – 49 [refused 3 rd interview after various arrangements] QL – 65 – withdrew before 2 nd interview	Reinterviewed 5/6 male 3/4 female NB – 37 [refused 3 rd interview after various arrangements] RS - 47 LI - 44 NN – 33 [incorrect diagnosis withdrew before 2 nd interview] NS 63	Reinterviewed 0/1 male 3/4 female TT – 21 [withdrew before 2 nd interview]	Reinterviewed 0/0 male 4/4 (female)	Reinterviewed 3/3(male) 1/ 2 (female) NE -69 (Asthma) NJ - 60+ (chronic skin condition and partial paralysis following stroke –too ill for 3 rd interview) TBI 38 Chest pains, frozen shoulder	
Total men =26	6 refused;1 abroad; 1 Bangladeshi;1 not followed up			1 refused		
Female	TI - 50+ [withdrew before 2 nd interview]	TC – 40 Mrs M – 28 HX – 50+ Mrs L – 50+ Not living at home at present	JK - 25-30 [moved out of area before 2 nd interview] UC - 31 ZI – 31 AB – 36	SQ – 26 IN – 60-70 QI – 55 Tu C – 66	OB - 43 (lump underarm believed to be extra tissue but open to rediagnosis) BC- 60+ ('burning in liver') [later diagnosed as cancer. Moved home by 3 rd interview and not traceable through family or community contacts]	
Total women = 24	2 refused	1 refused	1 refused 2 ineligible 1 abroad	2 refused		

5.6.4 Interviews with carers

As people with chronic illness were formally interviewed three times over the course of the research, by the time of the third interview the family member who was most involved in supporting an individual to gain information and make decisions about his or her health was often apparent. Patients were asked for consent to interview a carer and to identify who this person was. Contrary to the brief for the communication project, it was not possible to obtain consent to interview fifteen carers (half the original sample) as people with chronic illness often did not want to subject them to a research interview or else could not get their carer's consent. I carried out eleven semi-structured interviews with family members towards the end of the fieldwork period. By this time I had a fairly detailed picture of each person with chronic illness and could pursue particular issues that had arisen from patient interviews. All carers who were referred by the people with chronic illness agreed to be interviewed.

5.6.5 Professional interviews and 'shadowing'

As a way of getting to know the dynamics and organisation of health services for people with chronic illness in the fieldwork area, I spent some time interviewing and accompanying health professionals in a variety of healthcare settings (see Data Sources above). I chose particular contexts because they were relevant to the chronic illnesses in the patient sample, because certain professionals could give insights into the research questions or else because access was eased through someone already involved in the research.

In addition, people with chronic illness were asked to suggest influential professionals to whom I and my colleague could speak as a way of looking at their healthcare from a practitioner's perspective. Influential practitioners were not always as apparent from patient interviews as influential carers and patients showed more concern about giving consent to such interviews. There was evidence that people with chronic illness were worried about the consequences of being discussed and that they did not want to take up the time of professionals who they felt were already very busy. Nevertheless, consent to contact professionals was given by thirteen people with chronic illness. Six of them were with the same GP and two GPs would not agree to be interviewed. Consequently, six professionals – three GPs, two consultants and a community health worker – were interviewed in relation to eleven patients.

5.6.6 E-lists

I built up my membership of e-lists over time and these became far more numerous and significant in terms of the findings of this study after September 11th 2001. At the beginning of the research project, I was already subscribed to three e-lists for Muslims, two of which were academic and the third aimed mostly at disseminating faith teachings. I was invited to join various others over the course of the fieldwork period and membership of some lists appeared to attract invitations to others. One local community group also started an e-list for members to share information and ideas. This was also used to circulate minutes and notices of meetings, to discuss relevant current events and to forward messages received from other sources.

5.6.7 Ethical considerations

Data was collected for the study between 2000 and 2003, before the new Research Governance Framework (COREC 2004) came into force. Ethics Committee approval had been granted for the research both in primary and secondary care sites (see Appendix 3) and data protection legislation also had to be negotiated in some, but not all, parts of secondary care. This created a barrier to accessing patient records from one secondary care clinic. However, one of the individuals involved in the community ethnography was a member of NHS staff. She agreed to send off letters to a list of individuals identified for the study, but to which I could not have access, on my behalf. Fortunately, this helped identify a significant number of Pakistani people for the patient sample.

Apart from issues such as confidentiality and access to data, there are other ethical issues raised by the study. Greater accountability has been demanded by writers and activists in the fields of ethnicity, feminism and disability studies to avoid research that primarily serves the interests of researchers themselves. There are good reasons to question the motives of research in disadvantaged groups as these can disempower and seek to control those being researched (Barnes 1996; Hammersley 1992). Research accounts have been recognised as having a political aspect that works against research subjects if not based on an empowering and collegial relationship (Denzin and Lincoln 1994).

As already mentioned, there is justified cynicism within the Pakistani community about the value of research studies; research over the past two decades, whilst highlighting the needs of minority ethnic communities, have achieved few and piecemeal outcomes in mainstream

service provision (Mir et al 2001). Studies that take up the time and energy of people from this community whilst offering no tangible benefit to them risk reinforcing the perception that research is carried out primarily for the benefit of researchers. It is, perhaps, not surprising that some respondents took part mainly to support myself and my male colleague in our work rather than because they expected any benefits from the research.

Low expectations of research outcomes was a particular problem for this study, as my brief was to interview people with chronic illness on three separate occasions. I attempted to address the problem by offering to help respondents with health-related issues with which they might need support over the period of the study. This offer was taken up by a number of respondents. I became involved in a range of issues that people felt were relevant to their health, such as helping to pursue a claim for central heating, making a referral to the Community Health Council, providing transport and interpreting for two people at the diabetes clinic and looking into a support group for someone with a coronary condition. I faced some resistance to this approach by other members of the communication project team. However, as I was collecting valuable data through such activities this approach could also be justified as ethnographic data collection.

A second ethical issue was also raised through fieldwork. It became clear that a significant number of respondents with limited English felt vulnerable to having their trust abused by professionals, who might use information against them, or to being held responsible for things in which they had unwittingly become involved. For example, AB initially refused to take part in the research because she had heard an anecdote about a bilingual professional who had conspired against Pakistani parents to take their children into care. NI similarly expressed his fears about unexpected consequences after he gave consent for me to interview his GP. He asked, half-jokingly, “They won't come to take me away in handcuffs will they?”

There is evidence that a lower standard of professionalism may be applied to respondents who do not speak English well and who do not understand professional systems, as they are less likely to complain (Mir and Tovey 2003). Lack of ability in these two areas is sometimes confused with lack of intelligence. I was once told, for example, whilst working as a research interviewer, that the aims of a study should be explained in terms that were simplified to the extent of being untrue, ‘because people will only hear what they

understand'. Adopting this approach and bending the rules because one is unlikely to be held to account is clearly unethical. One could argue that these dynamics confirm the need for higher levels of accountability and for community involvement in research where such attitudes may exist.

These ethical concerns indicate a need for clarity about what researchers are trying to do and what they hope to achieve through their research. It is unhelpful to feel threatened by or resistant to the concerns of participants, rather it is important to acknowledge the political aspects of this kind of work and be prepared to justify the methodology and aims of a study in detail. I would argue that research questions and research design should both be informed by the priorities of people from this community (see Advantages and Drawbacks below). Their involvement in all aspects of the study, including dissemination, may help prevent abuse of the research process and raise its credibility within minority ethnic groups.

5.7 Data collection

Because of the varied sources of data (see Tables 1 and 2), a number of methods were used to generate and record information from each of the respondent groups. These are described in relation to each method below.

5.7.1 Observation and community-based fieldwork

I made fieldwork notes and observations during community-based ethnography and during professional 'shadowing' in clinical settings. The opportunity to observe respondents in community, clinical or domestic settings was a useful addition to the data which allowed me to compare an individual's description of his or her interactions in these settings with my own observations. I was also able to observe family-based communication during semi-structured interviews and, as these took place over a period of time, respondents and family members often became more relaxed the more contact we had. In addition, observation of community-based activity at particular sites gave insights into shared or diverse views about particular events or topics.

This kind of information was a valuable addition to the data. For example, observation of the Friday prayers and sermons at a mosque in the fieldwork area revealed how religious teachings might be interpreted in relation to particular events, the reaction of people in the

congregation to these events and also the wider social dynamics affecting the community. During one very significant sermon in relation to the September 11th terrorist incident in New York, the *imam*²⁵ expressed his condemnation of the attack and the lack of support for such acts from Islamic teachings. In the same sermon he referred to the suffering of Muslims in Palestine and Kashmir and condemned the state terrorism to which they were being subjected. All the women broke down in tears during this sermon and I noted that, to my knowledge, it was the first time a public statement had been made about the issue in the fieldwork area since the incident four days earlier. The lack of local leadership and of a community voice outside the mosque was brought into sharp focus by this situation.

I used various methods to make notes of this kind of data. For most observations I used a fieldwork notebook in which I recorded a detailed description of things that had happened on one page and my own interpretations or comments on the facing page. I recorded some observations on to the end of a tape if they related to semi-structured interviews so that they were available with the formal transcript of the interview. Where written material was available, for example, at meetings or literature about community organisations, I would collect these and write my own notes on the sheets themselves. My notes on what I had observed were, in effect, memos that contributed to initial analysis of the data (Strauss 1987). I used these fieldwork notebooks to keep a list of emergent themes, some of which I used to analyse data later on in the research process.

Hammersley and Atkinson (1995) emphasise the importance of observing the routine as well as the extraordinary and varying observation to different days, times and seasons so that the impact of events on each other is not neglected. At particular times of the year fieldwork interviews and observations were less easy to arrange than at others. Most respondents did not want to arrange interviews during Ramadan as many people stopped 'extra' activities in order to focus on worship and changes to family routines during this month. Similarly, professionals usually preferred to wait until after national holiday periods. However, in view of the need to include a wide range of temporal sampling I did arrange a small number of interviews with people who were happy to proceed with these during these periods. After Ramadan was over, I included questions about management of chronic illness during this month in the topic guide. This led to a number of findings about the impact of fasting on medication.

²⁵ see Glossary: Appendix 1

5.7.2 Semi-structured interviews

Although I carried out most of the interviews myself, I had some support for many of the male interviews from colleagues Ikhlāq Din and Hanif Ismail. I also had support from my project supervisor, Andrew Nocon, for some professional interviews. This enabled me to offer gender and language matched interviews as a way of maximising generation of material for analysis (Kelleher 1996). People with chronic illness and carers were offered language and gender-matched interviews although some were willing to be interviewed irrespective of gender matching. Some gender matched interviews were also arranged for professional and key informant interviews.

Interviewees decided on the location and time of the interviews; most patient and carer interviews were conducted in their homes and professional and key informant interviews were conducted at places of work in statutory and voluntary organisations. Topic guides were constructed to allow comparison of data from these different stakeholders (see Appendix 4). I and my colleagues ensured that all interviews were conducted in a relaxed and friendly atmosphere, taking into account the fact that a number of the people with chronic illness and carers had no previous experience of being interviewed.

As mentioned earlier, researchers also had to be prepared to address a lack of confidence in the research process and a level of suspicion, reasons for which have also been highlighted. My colleagues and I treated these concerns as reasonable and emphasised reassurances about confidentiality and plans for dissemination. Nevertheless, participants sometimes only took part out of a sense of loyalty – they wanted to ‘help’ the researchers and were pleased to see Pakistani people in professional jobs even though they showed little interest in the questions we were asking.

There was also a feeling that researchers should show similar loyalty to respondents by helping to meet their immediate needs. I was prepared to become involved in this way for the reasons outlined in ‘Approach to Fieldwork’ and ‘Ethical Issues’ above and I noticed that this had a very positive impact on my relationship with respondents in the patient sample. People with chronic illness held similar expectations of healthcare staff and these dynamics alerted us to an important issue in professional-patient relationships. The process of identifying need was often not considered a worthwhile activity unless linked to outcomes that improved people’s lives. Some respondents, for example, needed help with

longstanding problems in which a number of other professionals had already been involved without success. If researchers could not do anything about these issues, their reasons for asking about these problems was called into question:

- Q Do you want to ask any thing uncle?²⁶
- NE No we don't want to ask anything.
- NE's wife No we don't want to ask anything.
- NE We don't have any other demand. Our demand is to get us a house. If you could do that then thanks to you. If you can't do that then coming repeatedly is useless. Otherwise it is waste of time for you and us. The questions are fine but the illnesses don't go away with answering these questions.

(NE - male with asthma and coronary heart disease)

Interviews were conducted in English, Urdu, Punjabi and Mirpuri (a dialect spoken by many respondents who arrived from the Kashmir province of Pakistan). Both I and my male colleagues spoke at least two of these languages and understood all of them. Often combinations of these languages were used. For example, a Punjabi and Mirpuri speaker can hold a conversation without much difficulty and both will usually adapt their language slightly to use words that are common between both languages.

People with chronic illness sometimes used bilingual skills to switch between two languages during interviews because some ideas were easier to express or articulate in one language than another. For example, LI expressed his views about the events of September 11th 2001 in Punjabi although most of his interview was in English; ZI used a combination of English and Punjabi to talk about her own use of language and the way it is used by other Pakistani people she had come across to assess a person's social status.

Semi-structured interviews were tape-recorded and transcribed in all except six cases where respondents refused permission, usually citing reasons related to their worries about 'unexpected consequences' mentioned earlier. Interviews conducted in languages other than English were translated and transcribed into English. I developed guides for

²⁶ this extract is translated from Punjabi: the term 'uncle' is used to show respect for an elderly person

translators so that translations would reflect the meaning intended by the respondent rather than simply a literal translation.

Three separate interviews were conducted with Pakistani individuals with chronic illness over a period of 12 to 16 months. In the first round, 31 people took part in semi-structured interviews, followed by 22 in the second stage and 20 in the third and final stage. If respondents did not wish to take part in a further interview or to give consent for interviews with people who influenced their healthcare, they often simply said so. Similarly some respondents felt comfortable with rearranging times and asking for interviews to be pursued at a later date even when researchers had visited following an agreed arrangement.

In some cases, however, the researchers themselves needed a degree of sensitivity to hints that respondents did not wish to continue. A small number of people who were reluctant to continue as participants or to allow permission for others to be interviewed took some time to actually refuse. In a few cases, the researchers were in the difficult position of feeling that individuals did not want to go further with the research but having no direct statement about this. This resulted in missed appointments and attempts to rearrange meetings that eventually ended with a refusal. In two cases, it was clear that the respondents were annoyed that researchers had not read their previous actions as disguised refusals to take part.

This suggested that some respondents felt refusing outright to agree to a request for interview could be construed as bad manners. These individuals expected researchers to understand - after a number of failed appointments and telephone calls - that they no longer wished to participate. In two cases in which a male researcher continued to try to establish contact, the male respondent expressed anger that the process had not been ended. Failure to acknowledge non-verbal refusal could thus also be understood as bad manners. I noted that male Pakistani respondents felt less able to refuse a request for interview from me than from my male colleague. One respondent said the only reason he had agreed to be interviewed was because I was a 'sister', otherwise there was 'no way' he would have given consent.

The time taken up by interviews could be a reason for refusing consent, especially on second and third occasions. Concerns about taking up the time of others, such as doctors and family members, was also a reason not to give permission for them to be interviewed:

‘I don’t think the doctor will be able to you know, spare any time to do this’

(LI - male with diabetes)

As already highlighted, people with chronic illness also expressed worries that talking to professionals might have adverse consequences. Some respondents were concerned that I and my colleague might ‘pass on information about them’. Permission was usually given following reassurances that their own comments made during interviews would not be passed on. These dynamics are reflected in the feelings of vulnerability in relationships with professionals, expressed by a number of people in the patient sample (see Chapter 6)

The majority of the interviews were taped, with permission. Issues of confidentiality and anonymity were discussed as well as what would happen after the interview. Once the interview began, the tape recorder became secondary to the proceedings. However, a small number of interviewees – mostly women - refused to be recorded, usually citing their dislike of being taped or else fears about ‘unexpected consequences’. Although from my point of view, recording interviews ensured that little data was lost and I could focus better on people’s responses, some interviewees were unsure about the purpose of taped records. After an attempt to reassure and persuade them I accepted their decision.

Even respondents who agreed to have their interview recorded would sometimes ask me to switch off the tape for certain parts of the interview - not because they wanted the information to be ignored in relation to the research but because they did not want to have the information taped. Talking ‘off tape’, particularly about secret or private matters or about legal proceedings, was more acceptable to them. Where permission to tape was refused, I took brief notes and recorded my own version of the interview from these as soon as possible afterwards.

The three separate interviews of Pakistani people with chronic illness offered opportunities to gather in-depth data at a group and individual level. Successive interviews aimed to

build on significant themes, which had arisen in the previous set of interviews. It was also possible to tailor specific questions to individuals based on what they had previously said. The three interviews thus helped me to build up a very detailed picture of respondents along with an understanding of their most important concerns and values.

I noticed that a number of people with chronic illness repeated accounts of events or particular ideas in different interviews. I took this to indicate the importance and impact of these events or ideas on a respondent. For example, ZI recounted an anecdote from her childhood in two interviews, which supported her complaints about lack of care from her mother; CT told the same joke about 'village mentality' to show how he felt about some members of his community and QI repeated a story based on Islamic teachings, which she felt had had a big influence on her understanding of religion. The significance of these anecdotes to individuals was demonstrated in a way that a single interview could not have always shown.

At the same time as recognising the value of this number of interviews, however, I did have concerns about drawing on people's time so heavily and my reliance on altruism in a community that has less than its fair share of resources. A methodological strength could thus be seen as a weakness from a different perspective, particularly as best practice guidance about paying consumers in health research had not been considered when the project had been costed (INVOLVE 2004). This issue is discussed in more detail at the end of this chapter.

Semi-structured interviews with key informants and professionals, who had a better idea of the process, usually generated a good deal of valuable data. However, some people with chronic illness had little experience of research and could be bemused or perplexed by interview questions. Despite our best efforts, some participants could not or would not engage wholeheartedly with the research process. This was particularly (but not only) an issue with male respondents who had little formal education and with elderly respondents. Open-ended questions often generated very little response and it was clear that respondents were neither interested in the questions nor stimulated to share their feelings or experiences. My response to this was to introduce a different method of interview based on participatory techniques in order to try to generate better quality data. This method is described in detail in the following subsection.

5.7.3 Participatory techniques

Examples of the difficulties I and my colleagues faced in relation to semi-structured interviews with some Pakistani patients are given below:

- a) NS and QL seemed amused and gave joke answers to questions that asked about feelings or family dynamics.
- b) NC felt that talking at length was not appropriate unless he had something definite to say: 'There's no point just saying something for the sake of it'
- c) In response to specific questions IN and NJ, two elderly people with chronic illness, sometimes began to talk about other issues related to their health or about a certain word in the question but in an unrelated way.

These difficulties indicated that some respondents did not wish to answer direct questions about their feelings or family relationships or that they did not feel they had much to contribute to the research. The third example above suggests some people found it difficult to focus on the question being asked, perhaps because of age or illness. In each example, what appears clear is that for a variety of reasons these dynamics prevented interviews from being 'conversations with a purpose' (Burgess 1984) since individuals were not always involved in a conversation and interviews became more a question and answer session. In this situation, both my male colleague and I felt we were subjecting these individuals to research rather than helping them to participate in it.

As a way of addressing these problems I began to explore different ways of eliciting the views of research participants apart from semi-structured interviews. A more sophisticated approach to data generation was developed as a result of this iterative approach. Johnson and Webster (2000) recommend participatory research techniques as a way of involving people from socially excluded, particularly non-literate, groups in a process of which they may have little experience. This approach uses visual stimuli and practical activities to generate data about views and experiences, empowering participants to share their knowledge in a way that traditional research methods do not always achieve. These methods are described as participatory because they support respondents to take control of their interactions with researchers. The use of concrete keywords, taken from previous 'patient' interviews, was a very important means of achieving this kind of participation.

Johnson and Webster used the approach in projects on social exclusion and food poverty, however I felt the techniques they used could be adapted to address the questions I wanted to explore. I developed three activities based on these methods which I used in the third interviews (see Appendix Five):

- A map of the fieldwork area which I used to find out how much people knew about health facilities and community organisations in the area and their views about the quality of service they offered. The map was also used to find out about other places in the community that were important to health or social activity and the extent to which individuals mixed with people from other ethnic and religious groups.
- A set of cards developed from analysis of previous interviews, which identified problems people could face when trying to look after their health. Pictures as well as Urdu and English words were used on these cards. This allowed us to involve individuals who did not speak or read either language as well as those who were literate in one or both languages. Respondents were asked to identify cards which showed problems they faced and then to place them in priority order.
- A second set of cards in similar format was used to ask patients about influences on decision-making. I again developed keywords from the variety of influences mentioned in the full sample of previous interviews. Respondents were asked to identify the most important influence on their decision-making and place this in a central position. They then placed other cards as near or distant to this central card depending on the level of influence they felt each person or thing had.

These activities were tested in the User Advisory Group and were well-received. During fieldwork, respondents who were comfortable with semi-structured interviews generally felt comfortable with the cards and took control of the process. Willingness to take more control of deciding how to order the cards was sometimes a result of becoming more familiar with the activity. For example, NL and TBI began to tell the researcher where to put the card after originally feeling the researcher should 'put them wherever you like'.

The words on these cards acted as prompts but the method allowed a greater number of prompts than would be possible in a semi-structured interview. In addition the priority attached to each card was made explicit through the process of accepting or rejecting the cards and then placing them in a particular order. Data from the previous interviews reflected needs and problems but often not the order of priority in which they were held by patients. The cards also placed more pressure on individuals to be specific about difficulties they faced. Their comments in relation to a particular card helped in understanding what they saw as the underlying reason for an identified problem:

- NL Every thing is difficult for me.
- Q Which is difficult from these [cards]? ...
- NL Walking and talking both have become difficult for me.
- Q How? Is it because of the language?
- NL No I am old. I am seventy years old. I have breathing problems. The other thing is I am on medication. Doctor gives me the medicine but it doesn't have any effect.
- Q Right, so is 'treatment' the problem then?
- NL Treatment means, when somebody doesn't understand your illness then medicine doesn't do any good... The difficulty is in talking, difficulty is in time ... Doctor prescribes the wrong medicine
- Q Is that your family doctor or the doctor in the hospital as well?
- NL All of them... They all just pass their time. They don't give you the medicine.

(NL - male with coronary heart disease and diabetes)

The extract above is taken from an interview with a respondent who was at times difficult to follow. The use of cards in this interview enabled us to identify mobility, speech and treatment as three priority areas of difficulty in relation to this respondent's condition. The additional comments provide insight into the respondent's feelings that these are problems partly because of his age but also because the doctors who treat him do not give sufficient time or attention to understanding his condition and therefore cannot treat him appropriately. These ideas are supported elsewhere in this and other interviews with the respondent.

Similarly, TBl moved from stating a number of times that 'Nothing is difficult' to expressing in detail how he felt financial worries contributed to his illness by taking away his 'peace of mind' and ability to work less hours. He explained that these worries often occupied his thoughts but were a subject about which he spoke to no-one and this 'thinking' was also, he felt, a cause of illness.

This approach to communicating with respondents was therefore of value in drawing out the thoughts of individuals who generally did not communicate their thoughts and feelings in response to a straightforward question.

It was not entirely effective in all cases, however. A smaller number of respondents who did not speak in any depth during semi-structured interviews were also not stimulated to talk at any length through participatory methods. I also discovered that maps of the area were not easy to use for people who couldn't read or people with visual difficulties.

Interviewees were asked to evaluate these methods after the interview. Some respondents preferred straightforward questions and answers rather than the participatory approach, which they felt demanded more concentration and where the answers had to be more specific:

'I did find it harder, I am not sure how I should have answered youI have to read myself and then concentrate. I have to think a lot.'

(HX - female with diabetes)

However, others preferred the participatory techniques which they said they did not find difficult; overall better quality data was generated through this approach. In addition to encouraging greater participation from individual respondents, these activities allowed me to gather data that could be compared across the respondent group. This made it possible to construct a hierarchy of problems and influences on self-care management for the respondent group as a whole. The map exercise allowed me to compare the most important community sites for social and health activities and the level of knowledge about community-based organisations within the respondent group. Furthermore, the process of selecting cards inevitably prompted individuals to talk about their reasons for choosing a

particular card and revealed in more subtle detail the reasons why some problems or influences might be more significant than others.

5.7.4 Case studies/triangulation

For ten individuals from the final sample, an influential family member and/or an influential health professional was also interviewed. The themes pursued in these interviews emerged out of the data generated from the ongoing fieldwork. The central purpose was to explore the points of similarity and difference between different stakeholders, at the same time as broadening and deepening understanding of community and family based processes, in relation to chronic illness management.

Being able to speak to carers and professionals was an important way of allowing me to compare the different perspectives of these stakeholders. These different viewpoints are relevant to a number of areas, such as views of healthcare, understanding and management of the chronic condition, expectations of each other and the relationship of these issues to faith and other aspects of culture. The ability to compare what individuals had to say about these areas allowed me to explore the shared understandings and the differences that might influence their interactions.

Hammersley (1992) highlights the importance of understanding multiple perspectives as sources of information about phenomena being studied. Triangulation offers a way of being 'reasonably confident' (p50) about the validity of the claims to knowledge made by research. Whilst recognising that I needed to rely on my own cultural assumptions in order to interpret events and speech (and so the validity of findings from this thesis cannot be known with certainty), this method helped me to monitor my own assumptions and those of research participants and to develop a more sophisticated understanding of people's behaviour and beliefs.

Most respondents understood the value of gaining a range of views about an individual's treatment and healthcare. Reassurances about confidentiality also helped ease the concerns of some people with chronic illness about giving consent for this part of the research (see above). Some people did not, however, consent to other interviews usually because they were concerned that professionals and family members might not have or make the time to be interviewed. Respondents sometimes did not want to 'bother' their GP or family

members by allowing us to interview them, especially if they held no expectations of them that were not being fulfilled:

‘I don’t want anybody to get involved because of me, you know ... in other words why should I bother someone else for my sake, for sake of me, you know what I mean, from sorting out these problems out or you know, where I can sort out myself...’

(LI - male with diabetes)

The relationships I had built with Pakistani people in the patient sample could be very helpful to data collection. Many respondents welcomed this relationship and invited me to keep in touch in between interviews. In some cases respondents took up the offer of referrals to relevant community agencies that could help them with particular issues or problems they had identified. A number kept in touch with me about these issues in between interviews, particularly when the other agencies involved had not fulfilled their expectation that they would resolve the problem. Much information about the poor quality service they were receiving from overstretched community-based organisations was gathered in this way.

5.7.5 E-lists

Over the period of the study the amount of information from e-lists grew considerably and I organised messages into various themes, under which the majority fell. These themes were (in alphabetical order): community/ummah²⁷; gender; global issues; leadership; legislation; media; mobilisation; Muslim groups (subdivided into differing, feeling threatened, health, Leeds Muslim Forum); political lobbying; self-blame. Although I did not systematically code and analyse all messages from these lists, I did code and analyse messages from Leeds Muslim Forum. Messages from other e-list groups provided a context in which to test or validate some of the findings relating to the faith identity of Pakistani people in the fieldwork area. I drew on these particularly in relation to the broader context of being a Muslim in the UK (see Chapter 8).

²⁷ see Glossary: Appendix 1.

5.8 Approach to analysis

I used the five-stage 'framework approach' as the basis of a clear and transparent approach to analysis of data from each stage of the project (Ritchie and Spencer 1994). These stages are:

1. Familiarisation: a full review of transcripts and notes
2. Identification of key themes around which the data can be organised (the framework)
These themes were identified during initial analysis and from topic guide areas.
3. Indexing: application of themes to text.
4. Charting: use of headings and sub headings to build up a picture of the data as a whole.
5. Mapping and Interpretation: in which associations are clarified and explanations worked towards.

5.8.1 Coding and developing findings

Data from the range of collection methods highlighted previously was transcribed and transferred onto the NUD*IST software package and coded. I organised data under the umbrella of a main theme. I had identified these themes as relevant from the literature and from respondent interviews, ethnographic fieldwork and shadowing. Themes were used to code the data and, within each theme, related issues were given a sub-code. A total of 154 codes and sub-codes were built up as coding progressed.

The main codes were: personal details (age, gender, education employment ethnicity, and financial information); family relationships; diagnosis of most recent illness; information/decision-making; ideas about medicine; diet; exercise; knowledge of illness; talking about illness; meaning of illness; religion (extent of influence/practice, teachings about health and illness, religion and wellbeing, definition of Islam, sources of religious information, religious community, mobilisation, media, religious leadership); management of illness; community contact; being abroad; continuity; weather; advice; general talk (use of different languages and of religious expressions); private healthcare; routine; time and methodology.

At the stage of coding a systematic approach was taken to ensure that as much of the data would be included in analysis as possible. I was assisted during this process by my colleague, Ikhlaq Din. To ensure a degree of reliability and consistency, we double coded

ten per cent of all the transcripts and used these to resolve any discrepancies between our interpretations of codes.

Analysis was an ongoing element of the study as I continuously identified themes that could be built into second and third stage interviews and explored within ethnographic fieldwork. Once I had developed themes and sub-themes to organise data, I began using propositions from my fieldwork notebooks more extensively to establish and test propositions against the data. Printouts from the software package under each code were very helpful in bringing together supporting and disproving evidence for these propositions. These helped me also to develop hypotheses and explanations that were able to include various viewpoints (Silverman 1993). The mix of age, gender and ethnic backgrounds in the research team was also helpful in terms of challenging some of my ideas about how to interpret the data and this helped me achieve a more sophisticated understanding of the data during analysis (Kelleher 1996).

5.8.2 From description to analysis

In my final analysis of the whole dataset (see Table 1), I was concerned to reflect the perspectives of the different stakeholders and to integrate the different accounts relating to each theme (Silverman 1993). As already described, ten case studies, which triangulated the views of service professionals, service users and carers, formed an important part of the data and I used these to add to the insights provided by thematic analysis of the research material as a whole (Mason 1996). These case studies helped to demonstrate the relationships between different actors and themes and the consequences of these in the lives of people with chronic illness.

Ethnographic methodology was also helpful during analysis in relation to managing the constructions of knowledge in Islam and in sociological research, which are significantly different. As highlighted in Chapter 1, exploring the views of Muslims within a secular sociological framework means that Islam is treated as a social construction and Muslim understandings of truth and knowledge are considered functional in nature. For example, the understanding of chronic illness as a test from God is interpreted as a coping mechanism rather than a self-contained act to be interpreted in accordance with religious scriptures. An ethnographic approach goes some way towards enabling the two constructions of knowledge described in Chapter 1 to co-exist. It allows the adoption of a

framework which attempts to understand social groups on their own terms and emphasises the 'subjective meanings' of social agents (Hammersley and Atkinson 1995). At the stage of analysing and explaining beliefs, actions and interactions, the interplay between differing 'regimes of truth' is explored and differing views about what is true and false are balanced against each other. The validity of such views is explored irrespective of their origin and irrespective of how dominant or marginalized they may be in UK society as a whole.

I considered both the religious beliefs of Pakistani respondents and dominant views in the wider UK society about what is true and false in the context of the empirical data. I attempted to treat both frameworks as possible ways of knowing the world that may struggle for wider acceptance and resist each other in the process. Through such an approach I hoped to avoid analysis that naturalises and reproduces the inferior position given to Islam and the unequal social relations that disadvantage Pakistani communities in the UK (Said 1995; Donnelly 2002). At the same time, developing interpretations that balanced different perspectives helped me to increase the validity of findings.

Ways of increasing the generalisability of qualitative data have been discussed in the literature on this methodology (Schofield 1993). Within the analytical framework outlined above, I explored the range and frequency of responses on particular issues as a basis on which to generalise respondents' experience. This helped me to gain a sophisticated understanding of diversity in different respondent groups. The focus on everyday sites and situations in fieldwork observation and semi-structured interviews also helped to increase the generalisability of findings (Huberman and Miles 2002). My approach to analysis aimed to ensure the wider relevance of the research findings by engaging with and contributing to relevant current debates.

Having developed a number of findings from the data, I was faced with the task of developing these further in the Discussion (Chapter 9). I felt the best way to do this was to consider these findings in the context of recent literature and debates about inequalities in healthcare, inequalities in health and policy development. Over the last 18 months of my period of study, I began to collect articles and reports that I felt might be helpful to this discussion. The question I attempt to answer in each section of my discussion of findings is: 'What do these findings add to what is already known in each of these areas?' This question helped me move to a position where I could relate findings about the Pakistani

community to a wider context and could ground my analysis in existing debates about health inequalities, which currently pay little attention to religious or ethnic identity.

5.8.3 Reflexivity

In order to interpret data effectively, a self-conscious awareness of what is learned, how it has been learned and the social transactions that inform the production of such knowledge is needed. This involves suspending preconceptions about particular settings and people (Hammersley and Atkinson 1995). A researcher's own socio-historical position, however, reflects prejudices and pre-understanding; the validity of his or her interpretation will therefore always be relative to the paradigm within which research findings are placed (Harvey 1990).

My own position as a Pakistani Muslim living within the fieldwork area could be seen as either advantageous or detrimental to the research process. Hammersley and Atkinson (1995) argue that suspending preconceptions may be more difficult for a researcher working within his or her own society as the experience of estrangement may be integral to the process of learning. They argue that settings in one's own society may not allow adoption of the novice role, which aids learning, and it may be more difficult to suspend 'common sense' assumptions about the 'obvious'. This position to some extent assumes that inside knowledge of a culture can only be combined with an adequate level of objectivity by someone who is not a part of that culture. A further assumption that appears to underlie their claim is that researchers working within their own societies will feel like insiders in all contexts within which data is collected.

Chaudhary's (1997) reflections on her position as an ethnographer researching her own society describe a different experience. Significant differences, as well as similarities, exist between herself and the other Pakistani or Muslim people she encounters during her fieldwork. Different sub-groups within the Pakistani and Muslim community view her as an insider or an outsider depending on how closely they relate to her expressed views and appearance. Her position both as a Pakistani Muslim woman and a feminist researcher appears to provide her with personal experience, enabling a high level of involvement in the community, on the one hand and critical distance on the other. She operates from a position in which she faces a choice of paradigms from which to interpret the actions of others and is clearly not imprisoned within a single cultural perspective.

'Shifting subjectivities' (Chaudhary 1997) are, perhaps, what all ethnographers need to develop, no matter what their cultural background. Hammersley and Atkinson (1995) acknowledge that outsider and insider standpoints are to some extent myths related to moral arguments about exclusive researcher legitimacy for a particular group. There are clearly arguments to recommend both; the important consideration for me during analysis and interpretation of data was that I attempt to identify any assumptions I might myself make alongside the assumptions of those whom I observed and interviewed.

A reflexive approach was important at every stage of the study and not just during analysis. Throughout the research process I regularly and critically evaluated the framework in which I worked, particularly when it was clear that certain approaches to fieldwork did not work well. This helped me develop a more sophisticated methodology than that contained in the original research brief. Nevertheless, at the end of the study it is possible to evaluate the strengths and weaknesses of my approach and these are considered in more detail below.

5.9 Advantages and limitations of the methodology

As highlighted earlier, there is a need for research that is based on the priorities of people from this community to avoid studies that benefit researchers more than Pakistani people themselves. This raises the question of how appropriate the research questions and research methods for this study were to Pakistani people with chronic illness. The research questions for the communication project and for my own thesis were based on issues raised as important to people in this social group in previous studies (Ahmad 2000; Sheikh and Gatrad 2000; Muslim Council of Britain 2002). The primacy of faith identity to people in this group and lack of existing evidence about how faith influences healthcare and health inequalities suggests that exploring this area in relation to health is appropriate (Sheikh and Gatrad 2000).

The advantages of ethnographic methodology for researching abstract concepts such as culture and religion, and for capturing the complexity of lived experience, have been outlined in earlier sections. Ryan et al (2001) establish criteria for the evaluation of qualitative research on health, which relate to the validity, reliability, acceptability, generalisability and objectivity of techniques used. In terms of this study, the diverse range

of respondents and settings, which have been described in detail, and the use of triangulation, ensured validity and generalisability. I aimed to achieve reliability and objectivity by a systematic and documented collection of data, a reflexive approach at all stages of the research process and the involvement of another researcher in coding and development of themes. However, in relation to the acceptability of the research design to Pakistani people with chronic illness, there were a number of limitations that, with hindsight, I would address were I to repeat the study.

During fieldwork, it was apparent that practical help with their needs was the main priority of respondents in the patient sample. The methodology for the research, however, depended on individuals and groups within the community devoting time and resources for no practical return. Given that research on needs within minority ethnic communities has resulted in relatively few service development outcomes (Mir et al 2001), this relationship could be perceived as exploitative. From this perspective, the methodology reinforced the idea that research does not result in practical benefits for people from the Pakistani community.

Although I attempted to redress this and build in an element of reciprocity in my approach to fieldwork, in future studies in this community I would attempt to build this in more robustly. An approach that builds in practical support for research participants and uses this as a method for collecting data could help to incorporate the priorities of Pakistani people with chronic illness into research. This kind of methodology would be of direct benefit, at least, to research participants and is likely to help develop better knowledge for policymakers and practitioners about *how* to meet identified needs more effectively. I believe this approach is more justified than research that adds to a more and more sophisticated understanding of *what* these needs are, when they are not consistently being met in practice at even a basic level.

Were I to repeat the study, I would reduce the number of interviews with people with chronic illness to two (using participatory techniques as well as semi structured interviews in both) and would increase the amount of support I offered to help people with health related issues. This would enable me to explore community networks from their point of view and spend more time on informal contact that people regarded as relevant to their own health needs. In the original design of the study, the overview of community

networks began before the patient sample was identified. It was guided by key informants and by my own knowledge of the area, rather than by the people with chronic illness. The alternative approach would have strengthened the ethnographic methodology and would also have addressed the ethical concerns about reciprocity raised earlier.

Furthermore, I was unable to maintain a great deal of informal contact with most of the patient sample after this phase, simply because of the number of respondent groups that had to be covered. This meant that, although I gained useful knowledge about household family dynamics and some social activities I did not have the chance to observe interactions in community organisations and healthcare settings as much as I would have liked, and relied more on information from semi-structured interviews. There was also no time in the study to explore *biraderi*²⁸ connections, which emerged as the main source of social activity for many individuals. With hindsight, I believe the alternative approach to fieldwork would have addressed these limitations.

5.10 Conclusion

Ethnography is a useful way of researching the kinds of abstract questions posed by this study. However, a number of caveats apply to all research with people from disadvantaged groups to ensure that they are not perceived simply as the objects of study, that they can contribute effectively and that they are empowered by research projects.

The process of carrying out this study highlighted that relationships between researchers and Pakistani people with chronic illness can be indicative of patients' other relationships with health and social care professionals. Respondents are usually dissatisfied about engaging in interactions which are divorced from outcomes they perceive as relevant. Nevertheless, they may agree to take part in studies for a variety of reasons, such as politeness or loyalty to members of their own community. They may give consent even though they are fearful of unintended consequences and even though they feel vulnerable and powerless.

This suggests the need for higher levels of accountability in research with disempowered communities. In addition, researchers will need to be aware of the importance of

²⁸ see Glossary: Appendix 1

reciprocity and of building in safeguards to prevent methods that allow exploitation in the researcher-respondent relationship. Innovative methods of engaging and empowering people at all levels of a research project go some way to addressing these challenges and helping identify the priorities of people from these communities. The depth of detail achieved through data collection was made possible by a reflexive and iterative approach, which enabled me to adapt the original brief and restrict the fieldwork area, use a wider variety of data sources and introduce participatory research methods.

This chapter has raised a number of issues that emerged as important themes during the research period. These and other themes are explored in the following chapters, which present findings from the study. Data from different sources is combined around these themes in order to present an account that incorporates the perspectives of different stakeholders. This allows a more sophisticated analysis of processes and contexts than would otherwise be possible.

PART III: FINDINGS

Introduction

The impact of faith on individuals or social groups can be explored from a variety of angles. However, a useful way of assessing the everyday influence of faith identity is to examine the way it affects individual and social behaviour in relation to particular contexts and processes (Williams G 1993). Initial analysis of data for the study showed that, for people with chronic illness in the Pakistani community, a number of contexts are particularly relevant. Family, community and clinical settings are all likely to be significant in the experience of having and managing a chronic condition. Taking account of these different sites during further analysis allowed me to explore how faith may be more or less significant in each context.

In terms of examining processes, I have chosen communication and decision-making about chronic illness management as ways of exploring the influence of faith for a number of reasons, some of which have already been highlighted. Both these processes involve values and beliefs and both reveal ideas and assumptions that may be traced back to religious identity. At the same time, other influences on communication and decision-making may also be apparent so that the relative effect of religion is not exaggerated or essentialised. Exploring these two processes thus also allows the opportunity to assess the influence of faith alongside other aspects of identity such as ethnicity, gender, social class and age. Furthermore, analysis of communication between people in each of the respondent groups and the process through which they influenced decision-making about chronic illness management, reveals belief frameworks and expectations that people in each group have in common as well as diversity within and between each group.

The first two chapters of these findings present evidence from the study in relation to communication and decision-making about chronic illness management. In each chapter, the specific influence of religion is drawn out and considered alongside other influences on each process. The findings focus on the perspective of Pakistani people with chronic illness, however as both processes almost always involve social interactions, evidence and analysis includes the perspectives of people in other respondent groups.

Having considered the relative significance of faith beliefs on specific processes in chapters 6 and 7, Chapter 8 takes a broader, and at the same time more detailed, view of religious identity by exploring both shared understandings of Islam within the Pakistani community and the personal meaning of faith to individuals. This is an important context for policymakers and practitioners to understand. Without such understanding, stereotypes or a superficial understanding of a homogeneous 'Pakistani community' risk being used as a basis for service development. This can mean that the investment of time and resources to achieve improvements in health may fail to achieve significant results in reducing health inequalities.

Chapter 8 highlights the diversity that exists within the Pakistani community in the fieldwork area in relation to faith beliefs, as well as principles and values that are generally held in common. It explores spheres of social policy that are currently underdeveloped in relation to this social group and highlights possible reasons why present policies do not appear to be improving health outcomes.

The chapter also considers the social position of Muslims in the UK, both as perceived by Muslims themselves and by others in the wider society, including the media. Again, this context is important to an understanding of the relationship between faith and wellbeing. Findings provide evidence about the impact of Muslim identity on social relations outside the Muslim community. The chapter explores what it is like to be a Muslim in the UK at a personal, group and political level. Analysis of these findings highlights areas in which social policy may not only fail to address the concerns of Muslims in the UK, but also undermine the practice of their faith so that its potential use as a resource for individuals and groups is eroded.

Overall, my analysis of findings from the study attempts to take the abstract notion of faith and relate this to the lived experience of Pakistani people in the sample. These chapters present evidence about the relative influence of faith identity on health. They also offer in-depth consideration of personal and social understandings of Islam both within the Pakistani community and in the wider UK society. This analysis allows me to draw out, in the Discussion which follows, the implications of findings for current social policy on health inequalities and concrete suggestions about how this abstract notion can be addressed in policy and practice development.

Chapter 6: Communicating About Chronic Illness

6.1 Introduction

Communication about chronic illness is influenced by the meaning it holds for individuals (Williams G 1993). For people with chronic illness, the diagnosis and experience of chronic illness has physical, emotional and cognitive implications, and cultural background, including religious beliefs, influences how these are interpreted. Analysis of data revealed that the Pakistani patients in the sample associated illness with reduced physical ability and control and unwanted dependence on others. Some described a changed concept of their bodies as having become 'fat', 'useless' and 'deformed'. Patients also felt less emotional strength as a result of their condition and less able to tolerate distress or anxiety. Illness was further understood as a sign of ageing and a reminder of death. At the same time, for those whose faith influenced their interpretations, it was a reminder of the purpose of life and of the need for patience and continued gratitude to God at times of adversity. Such associations were stronger for those who had longstanding and multiple conditions, however, individuals with a single recently diagnosed condition shared similar ideas about chronic illness.

These understandings reflect evidence in the wider literature on chronic illness that point to conceptions of illness as imposing change at a personal and social level and on the identity of an individual (Bury 1982; Nettleton 1995). Analysis showed that respondents in the patient sample considered their chronic condition to be a personal matter about which communication was only initiated in order to obtain support to help them adapt to the impact of illness. Adapting involved not only adjusting to new physical and emotional demands and finding ways to manage these in everyday life, but also finding a balance between previous identity and the new role implied by the chronic condition.

Respondent narratives showed how the meaning of illness for patients influenced their communication about the condition. Ethnographic fieldwork enabled exploration of the different contexts in which communication took place and the underlying reasons different stakeholders felt such communication was or was not relevant to each context. For people with chronic illness, communication about the illness was related to the need to adjust to the demands of a condition and to manage it in everyday life. Interactions concerning

chronic illness within the family, with health professionals and in community settings therefore arose as a result of:

1. the need to seek legitimacy for the changes involved in adapting to chronic illness
2. physical difficulties arising from the condition
3. the emotional adjustment needed to manage the illness in everyday life
4. the need for information and advice to help understand and manage the condition

The presentation of findings in this chapter focuses on the perceptions of people with chronic illness but highlights areas of similarity or difference with other respondent groups, such as carers and health professionals. The chapter begins with an overview of different sites in which communication about chronic illness took place. Findings are then presented in four sections, related to the different areas of support outlined above, which triggered patients' need to communicate about their health. Within each section, the different contexts of family, community and clinical settings are considered. The relevance of faith identity to communication and to management of chronic illness is also highlighted throughout the chapter and its relative significance in relation to other influences assessed.

6.2 Context and communication

Respondent narratives showed that relationships within which communication about chronic illness took place could change over time. From one interview to another, an individual's criticisms of physicians or relatives, which had been strongly expressed six months before, could become much more mellow and positive by the time of the next interview. Nevertheless, there were certain features of communication within each context which remained common themes through the period of the study and these are the areas on which I focus in the analysis of different contexts below.

6.2.1 Family and community contexts

Most people with chronic illness talked to family members about their condition in relation to all four areas outlined in the introduction, if they felt that these relatives could offer them the kind of emotional, physical or practical support they needed. Talking to family members about their illness was usually considered more appropriate than discussing this within the wider community, particularly in view of the personal nature of some aspects of adjustment. Members of the same household and those with whom patients had shared their home in the past (such as parents or married children) were distinguished from other

relatives in relation to communication about chronic illness. However, even within families, patients might not initiate, or might discontinue, conversations about their condition if they felt that the consequence of doing so or the response they received was not supportive.

Family-based communication often involved negotiating new boundaries of interaction which took into account the effects of chronic illness. For example, many individuals mentioned not wanting to talk at all, even with family members, when in pain, as they became irritable and wanted to be left alone. Patients felt their general interpersonal skills were adversely affected by illness and associated reduced tolerance and less ability to concentrate and to remember things with their condition.

Often, most social activity by respondents took place within their *biraderi*²⁹. In this sense the *biraderi* could constitute the community in which many people were most active. This community could extend geographically across different cities in the UK as well as abroad to Pakistan and India. Neighbours and friends also fell within patients' wider social networks but contact was sometimes restricted by the need to maintain contact with relatives.

Conversations in this wider context often began with general questions about health, particularly in relation to individuals known to be ill. The influence of religion on understanding and expression was often apparent within such conversations. Religious expressions such as *Insha Allah*, ('God willing') *masha Allah*, (indicating happiness or approval) and greetings such as *Assalaamo alaykum* ('Peace be upon you') or *Khuda hafiz* ('God be with you') were common in both Punjabi, Urdu and English conversations and were used naturally within conversations about health, indicating the close link respondents often felt between their physical and spiritual life and the effect this had on how they understood health and illness. This association is discussed in more detail in Chapter 8. It is worth noting here, however, that religious expressions were often used as a means of offering reassurance and an appropriate response to the discussion of ill health.

²⁹ See Glossary: Appendix 1

Biraderi relatives, neighbours and friends were sometimes involved in recognising the first symptoms of a chronic condition. Once an illness had been diagnosed they would often ask about a patients' health and this was interpreted as showing concern. However, as in the wider literature on chronic illness (Nettleton 1995), patients often complained that people who lacked personal experience of the chronic condition did not appreciate its full impact and consequently showed a lack of sympathy or care. The far-reaching physical and emotional consequences of a chronic condition were seen as a personal issue by most patients, and they were unwilling to speak about these in public. This was partly because they found it depressing to constantly talk about the limitations their condition imposed and partly because of the delicate nature of adjustment that chronic illness involved. Close friends, particularly where patients' own family members were absent, and others who had been diagnosed with the same condition, were an exception to this because of the emotional support, and sometimes helpful information, they could offer.

Reduced mobility and energy, particularly when individuals had multiple conditions, affected their ability to maintain friendships and general interaction within community settings. This was to some extent countered by Islamic teachings which encourage visits to people who are ill, however, in the longer term, even within a religious group, these relationships within the wider community were often based on reciprocal arrangements which became difficult to continue:

'No one comes or goes. It's like when you are healthy every thing is fine and when you are poorly then it's quiet. People forget you if you are ill like the people in the mosque, the relatives. Friendships only exist when you are well. You come to mine I go to yours.'

(NJ - male patient with chronic skin condition/paralysis)

Social networks are acknowledged in current health policy as an important contributor to good health. The above findings show that the experience of chronic illness could significantly restrict the ability of a Pakistani individual to participate in community activity, thus decreasing the resources on which they could draw to help them manage their health.

6.2.2 *Interactions with professionals*

Reference to religious beliefs in clinical contexts was rare and, when this did occur, was related to specific acts that required adjustments to treatment or self-care, such as fasting or going on *Hajj*³⁰. In relation to professionals, communication was seen as appropriate in order to obtain relief for physical symptoms or for advice and information that would help with managing the chronic condition in daily life. GPs in particular were seen as providers of health solutions either through primary care or as a gateway to specialist healthcare. The diagnosis of chronic illness legitimised patients' requests for support in all the other areas and initiated new relationships in all contexts. Adjusting to more regular communication with health professionals than had been the case was a consequence of the new diagnosis for some individuals:

'I never used to go to the doctor before, it was very rare and now I seem to be going all the time, some women don't mind but I don't like talking all the time about it and going to the doctor's.'

(TC - female with diabetes)

This altered relationship also involved a different *kind* of communication with health professionals. Whereas in primary care patients initiated visits to seek support for specific problems, secondary care appointments were arranged to monitor patients at regular intervals. These were routine checks to enable health professionals to monitor self-care rather than for patients to access when they had concerns or wanted advice. Patients sometimes questioned the point of attending appointments that did not result in any treatment and there was evidence that patients and professionals sometimes had different understandings of the purpose of these visits:

'Pakistani patients often come to me feeling that they ought to have a whole list of symptoms because they are coming to see me, they ought to be telling me of all the things that are wrong with them whereas I am quite happy to see them even if they are saying that they are fine.'

(Diabetes consultant)

NB suggested that this mismatch of expectations could be a result of poor understanding of the healthcare system in the UK. Consultations in Pakistan would normally require payment to health professionals and this might reinforce the idea that appointments should be made when problems arise and that some treatment should be prescribed in response. Ethnic background was clearly relevant to this dynamic, however, social class and gender also influenced interactions in clinical settings. Individuals with chronic illness, especially women, were often supported in their interactions with health professionals by family members, who provided one or more of transport, language support, advocacy and explanation of professional advice. This support was provided mainly, though not exclusively, to individuals who had limited English, as well as to those who had little formal education and felt unfamiliar with healthcare systems. The unequal relationships between practitioners and people with chronic illness are explored later in this chapter.

Some healthcare contexts appeared to be unknown to the majority of Pakistani people. Recently introduced statutory advocacy services such as the Patient Advice and Liaison Service or Mental Health Advocates were never mentioned by people with chronic illness or carers and appeared to be unknown to them. Community-based fieldwork showed that staff in these services did not have the language skills to communicate with non-English speakers and were not providing information, support or advocacy to people within the Pakistani community.

6.3 Seeking legitimacy

As highlighted in the Introduction to this chapter, one of the four reasons why people with chronic illness communicated with carers and professionals about their condition was to seek legitimacy for the changes brought about by a chronic condition. The relevance of faith beliefs to this process becomes clear when one considers that moral approval and justification of an action are both implied in the act of conferring legitimacy (Williams G 1993). Such interactions generally occurred in relation to initial diagnosis and also to the need for adjustments to diet, which affected the family as a whole.

Diagnosis was considered to be very important by patients and a precursor to correct treatment. Delays in the diagnosis of South Asian patients have been highlighted in the literature on ethnicity and healthcare (Acheson 1998) and examples were found in the

³⁰ See Glossary: Appendix 1

patient sample too. BC was diagnosed with cancer more than a year after she had been told there was nothing wrong with her apart from being overweight. CT's lack of diagnosis for pains in his joints meant that no treatment could be offered that would address the underlying cause of his symptoms. In both these cases failure to diagnose a condition involved considerable distress, not only because of the pain caused by symptoms but also because of the implication that the patient's description of his or her physical condition was a subjective experience with no external reality.

Professionals who did not try a range of different approaches to diagnose the cause of pain or other symptoms of illness effectively denied legitimacy to a patient's perspective. Patients were therefore left feeling such practitioners did not believe and did not care about their distress.

Accurate diagnosis could be adversely affected by poor understanding of religious beliefs. In relation to psychiatric therapies, where cognition and beliefs are of great significance and might be expressed during counselling or assessments, there appeared to be very little practitioner understanding of Muslim beliefs. One key informant, who was a hospital interpreter, described her frustration during a psychiatric assessment. The psychiatrist misinterpreted a patient's frequent use of the word 'insha Allah', which the interpreter translated as 'God willing' to indicate that the patient believed God was speaking to him directly and the psychiatrist focussed on this during the session. The interpreter had to intervene to explain that Muslims very commonly used this term whenever they spoke about future events that they hoped would happen.

In respect of depression, legitimacy might also be denied by family members, even where a diagnosis had been made. People sometimes felt their families were not sympathetic to the diagnosis and in such cases legitimacy might only be offered by sympathetic individuals outside the immediate family. The study revealed that depression is a controversial diagnosis within the Pakistani community and is associated with personal behaviour and cognition, causes that are considered avoidable, rather than physical causes, over which individuals are believed to have less direct influence. All patients who had this diagnosis within the sample felt the behaviour of other individuals had contributed to their condition. At the same time they were blamed by others for interpreting events inaccurately, implying a distorted way of thinking. The cognitive influence of Islamic teachings could explain why

individuals were felt to be at fault in this respect. People with chronic illness often referred to the ability of faith to help them cope with anxiety and stress. Failure to cope therefore implies a failure to draw on this cognitive framework. Perhaps not surprisingly, patients diagnosed with depression sometimes found it more difficult to talk about their condition in any of the contexts explored in this study than patients with other chronic conditions. Observations during ethnographic fieldwork highlighted this tendency to attribute blame for depression to the individual receiving treatment and confirmed existing findings about the stigma surrounding this diagnosis in the Pakistani community (Wheeler 1998).

Accepting the significance of a condition and 'taking it seriously' was a precursor to family support for patients. Dietary change was an important area for legitimacy as it could often affect the family as a whole – cooking the same meal for everyone was far easier than making separate arrangements. TBl, for example, complained that his wife did not take his condition seriously and would not change her cooking to support him in eating a healthier diet. Where legitimacy was afforded to the individual with a chronic condition, families had sometimes changed their collective eating habits in order to accommodate the healthy eating advice given.

When family members were not involved in discussing such changes with practitioners, patients were left to negotiate these dynamics alone. Those who had not been able to enlist the support of family members were not able to insist on changes even though they felt unhappy that their needs were not being accommodated. This suggests that professionals may need to identify instances of poor family support and involve members of the household in discussions to promote a change in attitudes towards patients' self-care. Such professional intervention would add legitimacy to patients' own desires to make the required changes. A balance is likely to be needed between exploring the level of family support available to individuals and showing consideration for their privacy. The data suggests, however, that some people with chronic illness would value this kind of collaboration with professionals. Failure to probe in this area may deny individuals the support they need from professionals in order to enlist the help they need from family members to adapt to a changed personal condition.

6.4 Talking about physical difficulties

The second reason people with chronic illness talked to others about their condition was in order to get practical help with physical difficulties caused by their illness. This type of communication could be restricted in families when expectations about how much practical help should be offered were not shared by patients and family members. Patients' and carers' expectations and understandings of family relationships were often shaped by beliefs and values rooted in religious teachings and ethnic traditions. Differences in how these were interpreted by family members and the influence of the UK context on these values were highlighted during analysis. The first subsection below explores how people with chronic illness and carers may balance their ideas about duty and responsibility towards those who are ill, with the demands of daily life in the UK.

Further subsections relate to professional interaction and show that communication about physical difficulties with professionals could be restricted if these were of a personal nature or, more commonly, because of the poor levels of language support available. In contrast to family relationships, patients and professionals often lacked a common framework of beliefs or expectations about their relationship to each other. Unequal and uncertain relationships between patients and professionals, and patients' lack of skill in framing requests for help appropriately, could limit access to support for physical difficulties. Effective communication was often significantly hampered by a failure to overcome differences in belief frameworks and ethnic background. At the same time, the findings relating to help from professionals show that other influences, such as social class, are also of relevance to a sophisticated understanding of patient-practitioner interactions.

6.4.1 Help from family members

Daughters and daughters-in-law in particular provided support for physical tasks, even where they were not members of the same household, and helped people with chronic illness deal with the physical consequences of their chronic condition. Within families and at a community level there was a shared understanding that caring for a person who is ill, particularly a senior member of the household, demonstrates concern and care and is a social responsibility. Census figures reflect this understanding - the amount of time spent providing informal care is longer within South Asian groups than in other minority ethnic communities and similar to white groups, despite their younger profile (Office for National

Statistics 2004c)³¹. Within the Pakistani community, this understanding is reinforced, and perhaps founded on, religious teachings about caring for those in need, particularly family members and especially parents (The Qur'an 17:23-4; Hadith: Sahih Muslim 16/356)³². Cultural values within the UK were recognised by Pakistani respondents as being different in this respect - children were sometimes criticised by parents for not developing this understanding and patients sometimes felt this value was undermined by cultural norms in UK society:

A: She keeps coming to see me and she does things for me. She brings me food, and she does the shopping

Q: Do you like that?

A: Well, I like her doing it because – it's different, it's love...it's sort of - but I do things for her too... I have to do something in return. And I think it's being brought up here.

(QI - female with hypertension, diabetes and coronary heart disease)

Parents who depended on the physical ability or language and literacy skills of their older children could feel particularly vulnerable and undermined if their expectations about being cared for in ill-health were not met, and if they lost authority in their relationships with adult children.

Health professionals generally encouraged family involvement in helping individuals to manage their self-care and felt this involvement had practical value in reinforcing professional advice. However, practitioners did not understand the emotional benefits of family members providing care for patients. The significance of this kind of support in maintaining shared expectations about relationships between family members was also not understood, although these dynamics were treated sympathetically and not undermined:

³¹ This analysis does not explore differences between religious groups, reflecting the social policy emphasis on ethnicity as the dominant framework for understanding Pakistani communities (see Chapter 3)

³² see Pickthall 2000 and Siddiqi 2000

A: ...One thing I've picked up on ... the more I think about it is ... Pakistani women are very loathe to do their own blood sugars or insulins, and will rely on family members a lot more. I don't know why.... I always seem to be teaching the family rather than

A2: ... the woman will just refuse to do it

A: It's amazing, yeah, and it's amazing how many sons will do it as well.

A2: ...you can think of equally others who are fine and doing really well, but if I had to generalise, it would be older women who will be very reluctant to do things for themselves.

(Specialist diabetes nurses)

The above quotation suggest that age and gender are further factors that affect family communication about chronic illness management and that older Pakistani women may hold higher expectations of family support than other people with chronic illness. Again, a particular emphasis on care for mothers can be found in religious teachings and may explain this finding (The Qur'an 31:14).³³

Social norms about providing care for relatives who were ill were generally upheld but, in most families, carers and patients balanced this showing of concern for the patient against how much family members could practically do. The lifestyles of people with chronic illness were often markedly different from those of carers, who often worked or had multiple responsibilities in the home. People with chronic illness consequently worried about asking for support if they felt family members would misconstrue their request as criticism of the amount of help they provided. Most people generally tried not to make too many demands on the time of family carers, particularly those who did not live in the same household. However in some households this balance was not achieved and patients felt their family were 'too busy' to provide this care, with the implication that they were too busy to be concerned. This failure to uphold social and religious norms was usually associated with work and lifestyle patterns in the UK that undermined family care giving and encouraged materialism (see Chapter 8).

³³ see Pickthall 2000

6.4.2 *Help from professionals*

The majority of people with chronic illness did not approach health professionals for help in obtaining support for physical tasks they could no longer perform and most had not thought of asking their physician to refer them for services such as a home help. Communicating about physical problems in clinical settings was most often aimed at seeking relief for pain or discomfort. Patients felt they should tell professionals about physical problems they experienced and 'shouldn't hide these things' however this was often considered unavoidable rather than desirable and concerns about personal modesty could act as a barrier to communication. In one case, embarrassment about a very personal health problem delayed an elderly patients' consultation with her GP until the discomfort became considerable. Gender was not the only barrier to communication in this instance, as this patient had not informed her own daughter, the main carer, again because of the personal nature of her difficulty.

Although religious teachings encourage modesty, (The Qur'an 33:35)³⁴ the need to forgo this in order to receive advice on personal matters is acknowledged (Khan 1987 pp145-147) and most people did manage to overcome their embarrassment to take advice about personal health issues. Nevertheless, fieldwork indicated that concerns about modesty provided a rare instance where communication could be enhanced *because* practitioners did not share the same belief framework. Two women in the sample said they found embarrassing issues were especially difficult to discuss with males from their own community. This suggests that the lower expectations about modesty which were perceived to exist outside the Pakistani or Muslim community enabled communication that might otherwise not have taken place.

A number of other barriers to communication were identified in interactions between patients and health professionals during analysis. Findings revealed mismatches between professional expectations and patients' skills or experience. These mismatches meant that, for Pakistani patients, the simple act of talking to a health professional could be fraught with possibilities for communication failure because clinical procedures or cultures had not been adapted to address their needs. At times, but not always, these barriers involved reference to religious beliefs. Each of these barriers is considered in the following

³⁴ see Pickthall 2000

subsections and the various influences on communication explored to identify the extent to which religious beliefs affected interactions.

6.4.2.1 Language support

The most obvious barrier to communication was lack of language support. Inability to explain symptoms fully because of limited English affected how much patients told or were asked about difficulties they faced. This in turn affected how much access they had to appropriate healthcare. Family members who had ability in English, though not always fluent themselves, adopted the role of interpreter in all the families in the sample.

Problems with this kind of interpreting were often raised by professionals, who recognised that the limited skill and multiple roles of family interpreters could hinder accurate and reliable transfer of information. Nevertheless, they continued to prefer family interpreting in practice over the use of professional interpreters, who were available through a system run within secondary care. Health professionals acted as gatekeepers for this service and none of the 18 non-English speaking patients within the sample were offered interpreting support at clinic appointments, nor were they aware that this could be requested.

The poor organisation of interpreting services within secondary care was described as a barrier to its use: inconvenience, expense and poor co-ordination were offered as reasons why interpreting was not commonly offered to patients within clinics. Despite numerous communications from the Unit which organised this centrally funded resource, some staff also appeared to be misinformed about who paid for interpreters and why they should be used. A Specialist Nurse in one clinic, for example, who would regularly make decisions about whether or not to book interpreters, believed that the clinic budget would be used and restricted her use of interpreting as a result.

Low use of interpreting facilities was recognised by some, but not all, staff as a problem. This was sometimes a result of considering language support in terms of their own needs, rather than those of the person with whom they were communicating. On short visits when practitioners felt they had got their point across, an interpreter was not felt to be necessary and again the expense involved could be a reason for not arranging interpreters, who were paid by the hour. Patients' needs to communicate in these situations were not considered.

Another reason given for preferring family interpreting was to involve family members who could reinforce professional advice within family settings afterwards:

A: We encourage English speaking people to bring a family member, because what the person doesn't remember the family member might remember, or you know, they're the people that are gonna be living with it, and again, it's chronic illness management, the family and friends need to understand a little bit about it as well. So I find that it does, as long as the family members are willing to do that, it serves as a way for backing up what's been said as well

A2: And also you find that the family members are worried as well, so they want to participate and it allays their fears as well as the person with the diabetes.

(Specialist Nurse)

These reasons for involving family members in secondary care appointments are supported by the findings (see section on 'Advice and Information' below). However, they do not provide any arguments against the disadvantages of using family members as interpreters: disadvantages which had been widely disseminated within secondary care and which were repeated in the findings of this study (see below). The assumption that an interpreter was not needed in these circumstances was thus not based on any logical argument and implied that the prime reason for relatives' attendance was to assist professionals.

In the absence of language support, more use of testing might be made by physicians in order to make up for poor communication with patients. Patient narratives showed that they valued these tests for the objectivity and insight they provided. However, tests were not viewed by professionals as solving communication problems and could also be problematised for the delay they caused in obtaining and interpreting information, especially when unexpected results were found.

Although very few patients had previous experience of the interpreting service, in principle they were open to support from professional interpreters in place of family members, especially where relatives were busy because of other responsibilities. Support from family members often went beyond interpreting to advocacy, and to explaining and supporting

professional advice as well as monitoring patient concordance. People with chronic illness did, however, distinguish between direct information from a health professional and that received through family members, whose multiple roles might interfere with the way they passed on potentially worrying information:

A: There was an Indian nurse who asked me if I knew what I had come for... She then went on to explain everything in my own language, all of which I understood.... My daughter S knew what was happening and she would tell me but I didn't register it as much as when the nurse told me.... I mean she [the nurse] told me about every single thing openly, they [the children] didn't tell me openly, they said there was a suspicion ... reassuring me. Like 'Mum, there's nothing, they just suspect there might be this' She [the nurse] told me about the suspicion properly 'These are the things, this is what they suspect, it could be this'.

Q: What's the better approach?

A: The better approach is that I had a complete understanding

(Tu A - female with hypertension and chronic stomach pain)

The above extract highlights the value of medically trained staff who can communicate directly with patients. 'Complete understanding' is more likely to be achieved not only when information is fully explained but also when problems of conceptual equivalence and the difficulties in expressing meaning can be overcome (Ahmed A 2000). Though bilingual staff were few, the findings show that the potentially valuable resource they brought to healthcare services was often wasted following their appointment to new posts because there was insufficient knowledge within services about how to make best use of such individuals. Thus a bilingual staff member appointed to cardiology services, within the fieldwork area, was asked to carry out research into the needs of South Asian patients, even though these had already been well established by two other research studies in the same local area. Work to implement the findings of existing studies may well have been a better use of this professional's time-limited post.

Use of family interpreters could make a significant difference to the kind of interaction that took place in other ways than those already highlighted. Carers appeared to underestimate

not only the patient's need for information but also the impact of pain and discomfort and could be more passive in their interactions with health practitioners than patients themselves would have been. Carers could be less willing to challenge health professionals than patients themselves on this issue and more willing to accept professional assertions that nothing more could be done to relieve pain.

- Husband: When I go to the doctors, the doctors say they haven't got the medicine yet, so what's the point pressuring them when they haven't even got the medicine? It's useless then making a fuss.
- Q: (to patient) And what about if you could communicate in the same language, what would you say then?
- A: (laughs aloud) .. but I can't
- Q: If you could though?
- Husband: She'd argue with them what else!
- A: (laughs)
- Q: You mean you're not ready to argue but she would?
- Husband: Yes she'd argue, she'd say "I've been waiting for this medicine for a long time, you haven't got it, so what are you calling me here for all the time?"

(BC - female patient with stomach cancer)

Direct communication between patients and professionals is one way such challenges by patients could be conveyed more effectively than in the above instance. Findings in relation to direct communication are therefore considered in more detail in the next section.

6.4.2.2 *Direct communication*

Both patients and health professionals underlined the importance of being able to communicate directly with each other in a common language without third party intervention. Individuals in both these respondent groups felt that this kind of communication enabled them to express what they wanted to say better and to understand each other better. Professionals felt that direct interaction helped them assess the significance of symptoms to patients more accurately:

‘because it’s a two-way process isn’t it? Not only do I not understand them, obviously they don’t understand me as well.... getting a story through an interpreter is always difficult, because it’s how you tell it is part of the thing, it’s not what you say, it’s how you tell it and looking for the, the non-verbal clues sometimes, which is part of experience. And so it, it’s certainly generally true of anybody whose English is either not good, or limited in some way, that it does, does make things more difficult.’

(Consultant cardiologist)

Taken together, the accounts of patients, professionals and carers suggest that direct communication between health professionals and patients enables both parties to achieve the understanding they need in an interaction. A number of patients in the sample who did not speak English had deliberately chosen an Urdu or Punjabi speaking GP for this reason. GPs from the Pakistani community who formed part of the social networks of patients were often called upon for informal advice in community settings. However, only a small number of people in the sample had access to such individuals. The shared culture and informal contact with these GPs appeared to be important reasons why they were asked for advice about how to manage treatment in the context of faith-based practices:

‘I was sort of bombarded with phone calls in the evenings and in the local mosque, people taking me to the side and asking me questions and it was quite obvious that some people were apprehensive about approaching their own GPs and nurses about certain issues, issues to do with circumcision for example or what medication to take along with them when they’re going on hajj [pilgrimage] or what to do when they’re fasting and basically because they felt that their clinicians wouldn’t understand.’

(Key Informant Pakistani GP)

Some, though not all, practices in the fieldwork area had employed interpreters or bilingual receptionists where GPs did not share the language of their Pakistani patients. One practice used the NHS Language Line facility³⁵ to enable communication, though again

³⁵ see Chapter 3 for further details of this initiative

ethnographic fieldwork with health workers revealed that this new resource was often deliberately ignored by GPs whose patients had limited English.

In secondary care the opportunity for such direct interaction, though greatly valued, rarely occurred for people who had limited ability in English. Health practitioners often denied that religion or ethnicity had any effect on their communication with Pakistani patients and felt differences were related to 'class, education and age, rather than race' (Diabetes Nurse Specialist). This position denies legitimacy to ethnic or religious identity in relation to communication about healthcare, whilst other aspects of culture are seen as relevant. Some patients expressed similar statements about the impact of religious identity on healthcare communication. However, analysis of data from the study showed that ethnic and religious identity did inform the assumptions of both patients and professionals, not only in relation to their own views but also in terms of their responses to each other. For example, some professionals ascribed non-compliance with medication to religious values and also attributed such problems to the fact that a person was Asian rather than seeing their response as generic. The extract below shows that such assumptions - in this instance about why a Pakistani patient might resist transition from tablets to insulin in diabetes treatment - could be challenged by discussing the context in which patients made their choices.

A: It seemed to be his religious belief that he was happy to let his life take its toll and he wasn't really interested in the intervention.

Q: So was he taking medication?

A: He was on medication but wouldn't go on to the insulin injections.

Q: Oh right. Okay. So it wasn't, I mean his belief wasn't that you should just leave everything.

A: No..... Again that's across the board.... patients will take a tablet for anything, you know, and we're all a bit like that....Well, if you think of it in personal terms, if somebody said to me "You're going to have injections for the rest of your life." I mean, it'd take us a long time to ... adapt

(Diabetes Nurse Specialist)

Knowledge about the context in which Pakistani patients make decisions, and a willingness to see common ground as well as differences, can thus add an important element to successful communication. Failing to acknowledge this broader context essentialises religious beliefs so that they may be used to explain everything about a Pakistani patient (misunderstandings about the concept of fate and its relation to fatalism are discussed further in Chapter 7). Findings from this study show that Pakistani people with chronic illness use a range of frameworks when communicating. Religious beliefs constitute a significant framework but this exists alongside other influences on their identity such as gender, age, ethnicity and health status.

It should not be assumed that professionals from a South Asian background would automatically possess the knowledge and skills to communicate more effectively than in the above instance. Some South Asian staff did not share the same linguistic or cultural heritage as Pakistani patients, or, because of social class differences, did not demonstrate a sympathetic understanding of their lifestyles, and therefore failed to ease access to services.

Direct communication, whether through routine access to bilingual health professionals or because all Pakistani patients speak English fluently, is a long-term goal that does not address the immediate problems of most patients receiving healthcare for chronic illness. Currently, even less ideal procedures for easing communication through interpreting are not routine in secondary care clinics even though this service is, in theory, available. Racism was highlighted by a number of respondents as one reason for the poor development and delivery of services to this social group and this is therefore explored in more detail in the next section.

6.4.2.3 Racism

Interpreters often complained about resistance to using the service they provided and the politics of acting as a bridge between professionals and Pakistani patients. They felt that poor use of language support was often a reflection of the culture within particular clinics where the needs of Pakistani patients were not prioritised. This was acknowledged by a consultant within one clinic, where reasons for not using the service were described as an 'excuse' and the possibility of a more accessible service was accepted. Given the significant numbers of Pakistani patients in this clinic, there appeared to be no reason why bilingual

staff could not be employed for whole days to coincide with a number of appointments where language support might be required.

Staff within the unit that co-ordinated bilingual language support felt that there was an undercurrent of unspoken racism which led some professionals to resist using resources for patients who did not speak English. The issue of racism and how this affects relationships between professionals and patients is explored later in this chapter in relation to emotional support (see below). However, it is worth noting here that changes in the way language support is organised may address not only how professionals could more easily access the service, but also how opportunities to deny access for patients could be reduced. The organisation of healthcare in other areas also gave little priority to patients' needs over those of practitioners, often because of the difficult time constraints under which healthcare professionals worked. The influence of these constraints on interactions between people with chronic illness and practitioners is explored in the next subsection.

6.4.2.4 Time pressures

Health professionals' priorities following a new diagnosis included gathering information of the history and progression of the condition. The protocol for first visits to diabetes and cardiology clinics involved also passing on a great deal of general information about the illness and how to manage it in daily life as well as routine checks on blood pressure, weight and, in the diabetes clinic, sugar levels. The amount of information that had to be gathered from and given to patients could place health professionals involved in this part of service delivery under enormous time pressure with individual patients. Fieldwork shadowing of such staff highlighted the negative effect this had on discussing patients' own priorities.

In addition to time pressures, the fragmentation of services meant that if a patient gave information to the 'wrong' professional this could lead to delays in identifying problems or in diagnosing a condition. Patients were given responsibility to redirect problems back to their GP, rather than clinic staff liaising with GPs themselves. If patients waited until their next appointment with the GP (which evidence showed they did) rather than making an additional appointment or if they did not mention the problems again, the opportunity to follow up this information was lost.

Time pressures in primary and secondary care also meant that in order to access advice effectively, patients needed to ask well-focused questions at appropriate times so that they were taking up as little professional time as possible. This could cause problems for patients regardless of their ethnicity and differences seemed to relate to social class as well as ability in English. The following fieldwork notes illustrate how different approaches to raising concerns by white patients could result in very different responses by staff:

‘The nurse warned me about J before the clinic and said she hoped he would not ‘cause trouble’ J had brought a number of previous medicines with him in a bag, which he took out and showed [the nurse] before having his blood pressure taken. She became confused about how these medicines related to his current medication. It turned out that he had brought them to show her because they had been more effective than the ones he was taking now. Her advice was to throw them away through the chemist ...

... whilst having his blood pressure taken, one man obtained information about how this compared to the rest of the group, who he noticed had very much lower levels during exercise than he did. [The nurse] gave him the information and committed herself to mentioning the disparity to the consultant before his next appointment.’

(Fieldwork notes - Cardiology clinic)

The above extract suggests that the way an individual frames a request for assistance is important. In the second extract the patient, an IT consultant, waited until the nurse began taking his blood pressure before asking a specific question. This meant that the nurse did not feel that the time constraints under which she was operating were threatened. Nor did she become frustrated at having to tease out the problem, as in the first extract, and her responsiveness to the question asked was, therefore, far greater.

Not knowing how to ask was recognised by the nurse in question as a reason why patients sometimes did not ask questions. Evidence from the study showed that Pakistani patients were similarly not formulating their requests for support from professionals in a focused way and were further hindered by limited language which made it difficult to explain what they wanted to say in detail. In the limited time slot patients are allocated in primary or secondary care, inability to present sharply focused requests means that most people will

not receive any more than routine support even from health professionals who are, in principle, willing to help with problems. Asking for support without meeting these expectations about how to communicate was unlikely to elicit a response. AB's physician, for example, explained why she had not written to support AB's complaint about the traumatic and unprofessional treatment she had received during labour:

'I just felt her statement was not enough to get my attention or my immediate interest to write a report but I thought if somebody had interviewed her at the Advice Centre in her language and could give me some very focal points there then I might start to get interested and do something.'

(General Practitioner)

This finding highlights the issue of professional responsiveness and one reason why practitioners may engage better with some patients than with others. It is important that practitioners understand this dynamic if they are to improve practice. This aspect of communication between practitioners and Pakistani people with chronic illness is, therefore, explored further in the next section.

6.4.3 Professional responsiveness

In practice, focussed discussion in a shared language with mutual understanding of the impact of chronic illness, was not the reality for most patients. This kind of interaction, where it did take place, was usually in the context of primary care, where relationships between patients and professionals were generally far better developed than in secondary care. One particular GP in the fieldwork area had developed a highly valued relationship with a number of his Pakistani patients. His responsiveness to their priorities appeared to be an essential element in this relationship.

Generally, patients defined 'good doctors' as those who provided medication when requested and adapted treatment to their needs. Having concerns taken seriously was considered a positive feature of healthcare and failure to respond to these concerns, especially to pain and discomfort, reduced respect for professional opinions and consequently the level of physician influence in both primary and secondary care. Complaints that concerns were dismissed were more likely to relate to secondary care. For example, one patient felt his GP's attempts to pursue other treatment options, though

unsuccessful, were vital. He contrasted this with secondary care, where his persistence in requesting different treatment was interpreted as aggressiveness.

Patients interpreted failure to address pain and discomfort as failure to fulfil a duty of care. Trying and failing to find a suitable treatment was acceptable to patients but failing to try led to deep mistrust and accusations of experimenting on patients and of keeping drug companies in business. Insincerity in the professional caring role was also implied by such actions. Sincerity is a concept that resonates strongly with religious teachings in Islam and shared understandings in the Pakistani community about this concept are discussed in more detail in Chapter 8. Here, it is worth noting that individuals could feel that their own sincerity was brought into question by failure to accept the self-reported impact of pain and discomfort. According credibility, and responding accordingly, was thus an important foundation for collaboration between patients and doctors.

The unequal relationship that existed between patients and professionals could be a further barrier to lay-professional collaboration. Most patients perceived health professionals as controlling both how healthcare was provided and access to health services. Where practitioners were considered unresponsive or negligent, this reinforced the unequal power relationship. Patients often felt powerless to challenge them, either because they feared the consequences or did not have the skills or energy to complain. Official complaints by three patients in the original sample were referred back to the original members of staff involved – in two of these cases complete denial of the patient's version of events was the only response patients received. In the third case another member of staff supported the complaint and this appeared to be the reason why it was upheld. The difficult process of complaining, which required persistence and energy that was already in short supply, appeared likely to result in patients being told their complaint was unjustified unless professional support existed for their version of events. Two of these patients claimed mental health problems had originated in the abusive treatment to which they had been subjected during labour. The denial that any of their account was accurate again denied them credibility and further added to the distress they associated with these experiences.

Seeking help from community agencies to support complaints appeared to require as much persistence as dealing directly with healthcare agencies. Fieldwork revealed that community organisations lacked staff with the time or skills necessary to advocate for patients

effectively in such instances. The Community Health Council had no staff with bilingual skills and patients who had limited English were therefore reliant on a community organisation with bilingual staff in addition to act as a go-between. This meant that three separate organisations could be involved in a single complaint, and the patient would need to pursue the complaint through each one. Even where patients acted independently and dealt directly with the healthcare provider, the complaints procedure was too difficult, support to make a complaint too inadequate and the response too unhelpful to constitute an effective challenge to professional abuses of power. This procedure again reinforced patients' self-concept as powerless to challenge authority effectively and the pointlessness of engaging in such challenges.

This perception of those in positions of authority could influence communication and relationships in other ways too. There was evidence from the study that feeling vulnerable to professional power could lead to individuals and groups presenting what they thought professionals wanted to hear. At an individual level, fears about the consequences of disclosing that they had sought treatment elsewhere, led BC's family to withhold medical information they had been given whilst in Pakistan. At a community level, worrying about the possibility of losing an exercise class led one group of Pakistani women to tell an evaluator things they didn't really believe. In both of these cases, it is clear that individuals did not understand how professionals made decisions and did not realise the possible adverse consequences of withholding accurate information:

'The women had told her completely different things from what they had told [the group organiser]. She knew they didn't believe the kind of things they were telling her and yet they had said that they were willing to pay for the class, that they were quite happy wherever it was situated. Afterwards she had found out that they had said these things because they were afraid of losing the class.'

(Community fieldwork notes)

A similar theme of 'telling professionals what they want to hear' is raised in Chapter 8 which describes Pakistani community organisations packaging themselves in terms of ethnic identity because of known hostility to faith-based activity, particularly by Muslims. The issues explored in this section reveal a wide variety of barriers to effective communication between Pakistani people with chronic illness and health professionals.

Although language was often highlighted as the main barrier (by patients and professionals alike), underlying problems often related to empowerment and to uncertain relationships which, in many instances, appeared to be more relevant to communication than language.

In primary care, language could be less of an issue in any case as many patients chose GPs who shared their first language. This did not mean necessarily that they felt more empowered or shared other aspects of culture. Gender, class and religion were considered significant in terms of influencing the balance of power in doctor-patient relationships and how health practitioners treated individuals, whether or not they shared ethnicity or language. A key informant who had worked for several years as a bilingual liaison worker in primary care, felt that these variables influenced the kind of relationship a GP might develop with individual patients and underlie the dynamics of healthcare that was provided:

‘The GP’s perception of a particular family or a particular patient that influenced how the patient was treated or not treated. And I think that also acted as the catalyst of whether the patient was empowered or disempowered from asking the questions or participating in the particular chronic disease management clinics and services.’

(Co-ordinator of Bilingual Liaison Services)

This section has focused on communication about physical difficulties whilst also exploring dynamics that may be more generally relevant to communication in families and in clinical settings. It has highlighted the fact that organisational contexts can influence how an individual's needs are interpreted and acted upon. This necessarily involves power relationships which may work against Pakistani people with chronic illness. The following section looks at the third reason (given in the introduction to this chapter) that people with chronic illness talked about their condition to others – in order to seek emotional support in order to adjust to their changed situation.

6.5 Emotional support

6.5.1 Help from family and community

The emotional adjustment to a diagnosis of chronic illness was often something that affected not just patients but other members of the family. Before or immediately after diagnosis, family members, including patients, would provide reassurance to each other.

Protecting each other from worry could sometimes involve family members limiting expression of their feelings both verbally and through body language. Fear of worrying family members was often a reason why patients did not discuss their condition, especially with young children or with relatives who lived at a distance and would not have access to the reassurance and support of others.

The narratives of people with chronic illness showed a reduced ability to cope with emotional pressure because of the condition. In many cases individuals felt that distressing events in their lives had triggered the chronic illness, which became an additional source of anxiety. Patients who were in constant pain, in particular, felt that they could not tolerate any situation which upset them, even if they were not directly involved:

‘If anyone does anything wrong, then my head feels as though it’s going to erupt just like if someone outside ... were to tell their child off severely or smack them ... small things too. I don’t want anyone to do anything, I just want things to move along so I’m happy, and can remain calm and secure.’

(BC - female with cancer)

Constantly ‘thinking’ about these worries was understood by patients and carers alike to have a negative effect on wellbeing. Family members and close friends discouraged patients from dwelling on such thoughts, however, the way in which this discouragement was expressed was important. Simply telling a person to stop was not effective - TC stopped talking to her older children about her health problems because they criticised her for worrying, telling her to ‘just forget about it’. Where patients were encouraged to think of their experience in a wider context this was, however, felt to be helpful. Referring to others with the same condition could encourage a redirection of thought:

‘They said don’t even think about it. Don’t think about it at all ... this happens to most people not just you.’

(BB - male with coronary heart disease)

Faith provided the resources to redirect thought in this way. Initial responses to distressing events could be moderated by remembering religious scriptures which encouraged a particular way of responding and this provided an emotional distance from the event

which was clearly valued and had a lifelong impact. For example, accounts from the life of the Prophet Muhammad which demonstrated patience despite provocation:

‘I remembered that [*hadith*] from my childhood ... it’s very important to me. Because ... when I get angry with anybody or annoyed and I want to do something, you know, because I’m human, so I think of that and it really helps me.’

(QI - female with hypertension, arthritis and coronary heart disease)

Religious teachings thus had a clear cognitive influence and were described by respondents as influencing the way they understood and thought about events throughout their lives. This use of faith beliefs to achieve emotional distance and an objective perspective was encouraged as a response to diagnosis of a chronic condition:

‘She at least reassures me, like she might say “Never mind, Allah is in control, you will get better, don’t worry, these things happen”.’

(OB - female with undiagnosed lump)

6.5.2 Help from health professionals

Individuals sometimes referred to the emotional involvement of family members to distinguish these relationships from those with health professionals. The reassurance offered by health practitioners was valued but people with chronic illness usually did not think it was appropriate to discuss their anxieties in any depth in these contexts. Professional accounts confirmed that Pakistani patients did not discuss the psychological impact of coronary heart disease with practitioners in detail even though they might be asked directly. Data from semi-structured interviews and from shadowing professionals suggested a number of reasons for lack of discussion in this area, many of which reflect dynamics previously described in the section on communication about physical difficulties.

Many patients did not consider emotional support to be part of the remit of health professionals. Even when they spoke to physicians or social workers in relation to depression, interactions focused on complaints about those who had caused their disturbed mental state and on support or medication that would help rather than in-depth discussions about how they were feeling. Emotional 'pressure' was thus explained in relation to what patients believed to be its causes. Consequently, practical help from practitioners as well as

a listening ear was felt to be the most appropriate response. As ZI commented, being able to talk helped to make individuals feel better but 'talking doesn't solve the problem'. Further barriers to accessing emotional support related to the way requests for help were framed and to discrimination against Pakistani people with chronic illness. These two issues are explored in the following subsections.

6.5.2.1 Framing requests for emotional help

A possible reason for reluctance to discuss the psychological impact of chronic illness was suggested during fieldwork by a cardiac nurse. She drew a parallel with white patients from lower socio-economic groups and observed that these patients were also less forthcoming about their feelings. Fieldwork observation of one such patient in an 'in-depth consultation' suggested that this was not necessarily because patients did not want to discuss such matters but that sufficient encouragement to do so may not be given :

'Gary was asked "Do you have any matters that worry you emotionally? And is there anything that you're worried about or concerned about?" He said that he managed all right and his father had left him with a load of problems but that was the way life was.... Gary gave a number of hints that that the problems were things that were worries for him. Because he was shrugging his shoulders, perhaps at the same time and saying "that's just the way life is, you've got to deal with it". Laura [the rehabilitation nurse] did not follow up these problems. If Gary had focused solely on the fact that these problems worried him, perhaps Laura would have had to engage in this discussion.

(Notes from shadowing in Cardiology Unit)

The effective use of direct and focused requests for help from professionals has been discussed earlier. In situations where professionals are under time pressure, a patient's failure to ask unequivocally for emotional support may result in this area being sidestepped. This appears to affect people with chronic illness from any ethnic group. However, with Pakistani patients, further dynamics involving stereotyping and prejudice also appear to be involved.

6.5.2.2 *Racism*

The issue of racism has been discussed earlier in relation to denial of language support for people with limited English. With respect to emotional support and engagement, racism was experienced more widely and in more subtle ways. When Pakistani individuals directly requested help with depression, for example, practitioner assumptions about their family context could undermine a person's attempt to define his or her own emotional state. These assumptions also had consequences for the advice people received. AB had initially described her experience during labour to her health visitor who, seeing the great distress it had caused her, advised her to visit her GP. During her interview with a member of the research team, AB's physician realised on reflection that her own assumptions about AB's family life had led to offering more support for contraception than for what AB saw as the cause of her depression:

'I've only joined the practice in recent years and I can't claim that I know her and her family background solidly, ...and with language difficulties I've not been able to encourage her to tell me what's going on at home she's coming and just briefly telling me "I'm tired doctor, I'm a bit depressed" you know and when we go through it all, "yeah well you've got loads of kids haven't you and you've got housework and I understand your husband doesn't help".'

As with complaints of physical pain and discomfort, Pakistani patients may have to negotiate a professional assessment, not only of the extent of their emotional distress but also of its causes, before practitioner support is made available. Practitioners' limited knowledge of the lifestyle of their Pakistani patients mean that these assessments may be subjected to stereotypical views – in this instance about Muslim women's position in the family (see Chapter 7 for further discussion of this stereotype). Furthermore, the need for practical support to deal with the causes of depression may not be recognised by professionals; despite the situation AB described, neither the health visitor nor AB's GP made her aware that she could register a complaint against the hospital, an option she took up immediately she realised it was possible.

Emotional support was most likely to be offered to people with chronic illness in the context of a positive relationship with healthcare providers. Such relationships were more often mentioned by English speakers in relation to secondary care, where fewer South

Asian professionals were mentioned by respondents. However, language was not the sole determinant of positive relationships and individuals with limited English often developed very good relationships through the force of their personalities:

‘Every time she’s been into hospital she’s really got on with the nurses really well. And they’ve laughed and they’ve joked with her and they’ve, I mean the nurses have kissed her, you know, on the forehead and she’s kissed them and it’s just, she feels so at home when she’s there and she thanks the nurses and doctors quite often and she’s, I mean she did say to the nurses before she left that, she did say to them that you know, “I don’t feel I need my, my sons and daughters to actually come down and see me because I just feel so well and at home here” and they’re really pleased to hear that.’

(Carer of TuC (female with hypertension))

Fieldwork observation and interview data showed that patients generally took the lead from professionals about how much to discuss and the level of informality that was appropriate. Practitioner accounts suggested that Pakistani patients could receive little encouragement to develop friendly relationships either with staff or other patients in group situations. Observation of a chiropodist’s interaction with a white patient was notable for the ease and openness that had developed between patient and professional, who were on first name terms and chatted about self-care in the context of the patient’s family life. The same professional remarked that she could sit in silence during the entire period when she attended a Pakistani patient, even where a family member who could speak English was present.

Another nurse commented that group dynamics within the cardiac rehabilitation groups she ran often excluded South Asian patients unless they took the initiative to push themselves forward and participate in the informal conversations that took place between members. These dynamics signal assumptions about the relationship between individuals from Pakistani and white communities. The evidence suggests that, even before interactions took place, Pakistani individuals could be treated as ‘different’ and barriers to friendly relationships could be erected. During fieldwork, few examples were noted of groups in which members of Pakistani communities were encouraged to mix socially with people from other than South Asian backgrounds. Evidence showed that individuals who

had tried to maintain social contact with white friends or social groups experienced insensitivity and undermining of their values by those with whom they tried to interact, as well as lack of support to challenge racism within a group.

Similar dynamics were reflected in the interactions between patients and the wider communities in which they lived. Almost all the Pakistani individuals in the sample said they valued the chance to mix with people from other ethnic backgrounds. However, apart from work situations, the only context in which this regularly appeared to take place was in the exchange of greetings with neighbours. There were additionally many accounts of racism in social contexts narrated by patients and those working within community-based organisations:

‘I feel afraid of them. We want them to call us, we want them to be friendly towards us but they don’t. At my children’s school they will never say hello to us. Instead they’re ready to hit us. The other day I was going to an appointment at the doctor’s with my son, he’s 12, and a boy who was about 17 started calling us from the bottom of the street just near the doctor’s surgery, it’s quite a dangerous place down there, he said ‘Come over here!’ and I said ‘Why?’ he said ‘Because I want to beat up your son’.

My son felt frightened, he’s a quiet boy, so we had to take the long way round on the way back so that we wouldn’t bump into him again. ... You can’t go on your own. You have to go in a group of women or else get a man to take you in the car.

(UC - female with depression/migraine)

The wider social context is significant because it is likely to be reflected within clinical settings. Professional cultures have already been mentioned in relation to poor use of interpreting services. Patients sometimes felt that the culture of a whole ward or unit influenced how practitioners within it interacted with Pakistani patients and poor relationships in secondary care settings were sometimes linked to the attitudes of staff generally within a unit. Racism and prejudice which was communicated verbally in patients’ neighbourhoods could thus be expressed non-verbally and less blatantly in clinical settings. Respondents often found it difficult to be certain that an apparent lack of

concern about their welfare and unwillingness to enter into a supportive relationship was racism. However, differences in the way they were treated in relation to white patients led some to believe that this behaviour indicated discrimination. JK described the trauma of a caesarean operation with inadequate anaesthetic, which she believed had resulted because of prejudice:

‘When the baby was delivered it was like it was taking up my ribs, I went completely floppy because I'd screamed so much, they put more painkiller in at the end and I didn't feel the stitches but I felt everything during the delivery’.

‘I asked why she felt the senior Doctor had not paid any attention to her, she said ‘I think he was being racist’... when she had been prepared for her caesarean, the staff had then taken everything off again, even though she had been in labour all night, white ladies were seen before her and the Doctor was angry when she began to cry and scream on the ward that she was in pain.’

(JK - female with depression)

Pakistani respondents also understood that racial and religious discrimination could be closely linked and accounts of prejudice often spoke about both elements together. Discussion of religious prejudice stimulated accounts both from personal experience and the experience of other Muslims. The nature of this discrimination was pervasive – respondent accounts reflected a perception that it was inescapable and permeated all areas of their experience involving relations with the general population: employment, education, housing, neighbourhoods, relations with the police and justice system, complaints procedures, travel and tourism, were all mentioned as being tainted by racism and prejudice:

'It's always there whichever walk of life you know, you can tell, for somebody like me I've been here 37 years, I have been involved with, I've done everything here, I've been ... I would say a 'bad boy' also for some years you know I never used to speak to our own people, I was more western than an Asian type you know but even then I noticed that okay while you're with those people they're okay but .. they don't accept you for what you are...this is something that is national, you can't just put it to one individual

(NT - male with coronary heart disease)

This level of prejudice is clearly relevant to general wellbeing; many of the areas in which Pakistani people experienced discrimination are described as relevant to health in the NHS Plan (Department of Health 2000). The relationship between religion and wellbeing and the influence of religious prejudice on members of the Pakistani community is therefore explored in more detail in Chapter 8.

The following final section looks at the fourth reason that people with a chronic condition communicated with carers and professionals about their condition. As highlighted in the introduction to this chapter, this area of interaction involved receiving or seeking advice and information. Differences in the perceived purpose of advice and information are explored and reveal that, for practitioners, this was to increase responsibility for self-care in patients and to achieve compliance. For people with chronic illness and carers, advice and information was sought in order to understand their situation better and to incorporate treatment alongside other important areas of their lives. Self-care and treatment were thus considered by patients in the context of their daily lives but this context was not always given adequate attention by health professionals.

6.6 Advice and information

The impact of a chronic condition could include a reduced ability to take in advice and give accurate information. The support of a family member was consequently considered important by people with chronic illness and their carers especially where there was a possibility of being misunderstood by professionals. This misunderstanding could occur not only because of language differences but also because practitioners might not always make allowances for an individual's emotional state, which could be affected by fear or

shock. The emphasis on self-care in professional advice could sometimes ignore this vital input from carers to the emotional wellbeing of a person who was chronically ill.

As with interactions in which patients sought treatment, practitioners and patients both relied on English-speaking family members to explain medication and to relay information where English was a barrier. However, a number of patients, particularly men, made do with their own limited English in consultations. This meant they were unable not only to explain their problems adequately but also to fully understand advice and information. One health professional noted that patients with limited English did not ask questions in as much depth as other patients and often 'just agreed with everything'. 'In-depth' consultations following cardiac rehabilitation could be carried out without interpreting support in such instances and this was treated as an acceptable level of communication despite the possibly serious consequences if patients had not understood the advice and information given.

'I did think there were little things he missed as I was talking to him, doing his individual talk.'

(Specialist cardiac nurse)

Family members who provided significant language support and liaison between patients and clinicians, could, nevertheless, sometimes feel excluded from important information about their relative's health. NC's daughter, for example, was regularly in touch with the cardiology unit who rang her after appointments to tell her about her father's medication changes. However, she did not know about a diagnosis of hypertension until he himself told her. As noted, earlier, carer involvement in the treatment of Pakistani people with chronic illness thus seemed to be perceived by professionals as primarily to ease communication between patients and professionals rather than to support the self-care of patients.

Carers often did not feel they knew much about the condition and sometimes expressed the wish to speak to health professionals in order to understand the illness better. Such knowledge was considered useful not only to support their relative but also to increase awareness in relation to their own health. The data showed that health professionals sometimes adopted an educational role with patients rather than their carers and explained

chronic illness in relation to the internal workings of the body in detail. People with chronic illness retained and valued this type of information. However, some respondents could also indicate little understanding of the condition or its prognosis and clearly had a confused understanding of their illness:

‘The doctor says that the heart cleans the nourishment of the whole [body] ... and that is why I have a lot of coughing. It’s not so much because of the asthma but because of that, because of the heart.’

(NE - male with asthma and coronary heart disease)

Some key informants felt that empowering patients to take the initiative in consultations with health professionals could be a further way of increasing the amount of advice and information they were given. They suggested that patients from higher social class backgrounds in all ethnic groups achieved this by being more assertive and having higher expectations than other service users. The findings support this view and suggest that patients may lack assertiveness because they are unsure of the boundaries of appropriate relationships with practitioners. There was evidence that increasing patients’ awareness of these boundaries and of their rights within them could encourage patients to feel more in control of consultations:

‘She [community speaker] said I should tell the GP and should not be afraid of asking anything, I could take up to 15 minutes, it is my choice, it is possible to take longer than 15 minutes ... I thought it was very good, at least we know now we can take that long.’

(HX, female with diabetes)

These findings suggest that a better understanding of the nature of patient-practitioner relationships and being accorded ‘permission’ is a prerequisite to such assertiveness. The ability to be assertive is in turn likely to increase the amount of information and advice people with chronic illness feel able to request and thus the degree to which they feel able to take responsibility for self-care.

Evidence from the study showed that the range of reliable information sources available is a further factor in this respect. Those individuals who advocated a significant role for

themselves in relation to their health did so because they had literacy skills or the support of family members who could access information from a range of sources apart from primary or secondary care staff. For those who did not have these skills, the availability of reliable alternative sources of advice was limited and patients in this position felt more dependent on professionals, particularly their GPs. Patients and carers both recognised dangers in relying solely on advice from physicians, who might forget multiple conditions and prescribe inappropriate medication:

‘Sometimes they give the medicine and when you bring it home and read the leaflet, it says on it ‘not good for diabetic people’. So it goes out of their mind, they forget. This is where if you know and you can read then you should ask somebody whether it is good for you or not or ask the doctor if there could be any harm or side effects to the medicine.’

Carer of IN (female with chronic skin condition and suspected hypertension)

There were very few, if any, alternative sources of reliable advice or information for patients without literacy skills. Without these skills, relationships with others were a vital means of building up knowledge of the condition and of how to manage self-care. However, patients did not accept advice indiscriminately and generally limited themselves to their GP as the main source of such information (see Chapter 7 for exploration of the reasons for this). Even patients with literacy skills relied on physicians to provide specific rather than general advice. This suggests that easy access to other health professionals who could offer such advice would ease pressure on GP appointments at the same time as providing additional support to patients.

A further important aspect of interactions involving advice or information concerns the level of concordance about treatment between practitioners and people with chronic illnesses. Findings on this are presented in the following subsection.

6.6.1 Compliance and concordance

The process of concordance involves practitioners and patients in negotiating treatment that is mutually acceptable and takes account of the concerns and priorities of each party and the context of patients’ lives (Stevenson et al 2000). This process often appeared to be absent from professional interactions about treatment with Pakistani people. An

expectation of compliance - where people with chronic illness simply follow professional advice - rather than a willingness to negotiate was often apparent. Professionals sometimes felt that, once patients had been given information, failure to act upon it indicated that they did not wish to follow the advice rather than a need for negotiation. Although the kind of information that should be given to each patient was clearly outlined and sometimes organised in packs for patients, procedures for following up this advice appeared to be far less considered and not subject to policy processes. In particular, there was significant uncertainty about what to do in situations where it became clear that people were not acting on advice given. Where follow up sessions with patients took place these could offer additional information about family dynamics, which have already been highlighted as relevant to dietary changes. However, if individuals did not offer information themselves about why they were not following dietary advice, professionals could feel 'stuck'.

Health practitioners expressed frustration when professional advice was not taken but were sometimes unclear about why this was so. This suggests that compliance was expected without adequate exploration of possible barriers to following professional advice. Their accounts highlighted their own need for information, which was often not being met:

'You don't get to the real reason behind why they're not able to make these changes. And that's ... quite hard, because you don't know really how much to push them on. You know, trying to explore those issues say. Because somebody, ... if they're not proffering the information to you, then it can be quite difficult to sort of keep questioning ... you do feel sometimes you get very much a surface picture and there is a lot more going on underneath, definitely ... it can be family dynamics and things like that you might not feel comfortable broaching, especially, you know, for example, if it was ... you know, a husband and wife ... and you feel that perhaps the wife is not telling you everything. But she might not because her husband is there or, you know those kinds of things. And you feel ... 'I don't want to question you about that if you feel uncomfortable about telling me.'

(Dietician)

In the area of dietary change the data shows strong family influence on decision-making by people with chronic illness (see Chapter 7). Yet advice within both primary and secondary

care was being given at the level of individual patients rather than families. Ability to implement the changes being advised therefore depended on whether the patient could control or obtain support for these changes in family settings. The lack of dialogue on this issue could mean that, not only was the opportunity to involve family members missed but also, as in the extract above, professionals used their own, often negative, ideas about Pakistani families, and particularly the position of women within them, to interpret family dynamics in relation to self-care.

Communication about treatment was affected by religious identity in other ways. Patients sometimes expected health professionals to consider acts such as fasting to be unimportant. Consequently, they did not consult their doctors about how to manage treatment in this situation for fear that they would be advised not to fast. These respondents felt that professional advice in relation to religious obligations would be subjective rather than impartial and inclined towards undermining rather than supporting their faith.

Although there was evidence that racism influenced the healthcare of Pakistani patients (see the section on 'Emotional Support' in this chapter) the study also provided evidence that health professionals could be more sensitive to religious practices than many Muslim patients anticipated. Those individuals who did consult their GPs or hospital doctors were usually not discouraged from fasting if they felt they had the energy; Dr N, a consultant in coronary heart disease, took a holistic view of religious observance, which he felt was overall a positive factor in relation to health. The difference in diet during Ramadan, even if it involved more fatty foods, was in his view less significant than diet over the rest of the year. This engagement in the process of balancing treatment with religious observance was, however, not an approach taken by most health professionals, who tended to treat such decisions as a personal matter to be left to the patient's discretion. (The consequences of this position are discussed further in Chapter 7). Patients often contributed to this lack of dialogue through their own assumptions about health professionals who did not share their cultural background.

Professional hesitation to explore family dynamics may not relate to Pakistani families alone (Walsh 1998), although the findings about decision-making indicate that cultural differences between patients and professionals made such discussions more unlikely (see

Chapter 7). Speaking about family dynamics anyway, particularly when they illustrated little support for patients, could be difficult in the context of a short interaction between patients and professionals who had little or no relationship with each other. It is not surprising, for example, that the richest data on family dynamics for this study was obtained during third interviews and by comparing carers' and patients' accounts.

Practitioners' accounts further demonstrated reluctant resistance to such interactions because of the time pressures under which they worked. Information given to people with chronic illness following new diagnosis was, as mentioned earlier, often very extensive. In contrast, information to, rather than from, health professionals was very limited, not only in terms of how much professionals requested but also the time made available to obtain this information. Health practitioners had very limited time and numerous patients with whom to go through the same procedure. Providing rather than obtaining information was therefore given priority in interactions:

Although it would be lovely to let them do a bit more talking, but in the harsh face of reality, you've got a lot of information to give and you've got a very short space of time to do it in. So it tends to be us doing most of the talking

Dietician

Patients recognised the time pressures on health professionals and that this could hinder ability to discuss problems adequately. Respondents often felt lack of dialogue with physicians was understandable, given these pressures. However, they also recognised that this decreased the quality of care they received. The long-term consequences of this would appear to have adverse implications for the use of healthcare resources. Where family dynamics are important to self-care, the findings suggest that increased concordance, and therefore reduced future complications, is likely to make the investment of professional time to involve family members and to discuss these dynamics a productive and effective use of NHS resources.

6.7 Conclusion

For Pakistani people with chronic illness, communication in families, communities and in clinical settings involves a complex mix of expectations and purposes. The four areas, identified at the beginning of this chapter, that underlie patients' need to communicate

about their condition have been explored separately, however analysis reveals that common threads run through each type of communication. Although people with chronic illness might seek different kinds of support from people in other respondent groups, the main purpose of communicating in all cases is to seek practical and emotional help with incorporating necessary changes into daily life. Context is important when negotiating such support and people with chronic illness constantly adapt their communication to the demands of different contexts.

The findings reveal that reference to faith is considered part of an appropriate response to a diagnosis of chronic illness for Pakistani people. Religious beliefs provide a therapeutic resource and can offer individuals an emotional distance from the chronic illness by placing it in the wider context of human experience as a whole. The ability to distance oneself from a chronic condition in order to cope with its effects is a resource in European culture too (see Bury 1982), however for Pakistani people this feature of culture is strongly connected to faith beliefs.

Religious teachings provide meaning to the experience of illness and can encourage ways of responding that decrease anxiety and depression. This may be the case even when individuals have been diagnosed with depression, which is not recognised as an illness by everyone within the Pakistani community and is often perceived as arising from faulty cognition or lack of faith. Respondents with depression, nevertheless, draw on religious belief frameworks to help them cope with the criticisms they faced and with the condition itself.

Findings suggest that effective management of a chronic condition is perceived by patients, carers and practitioners alike to be an essential aim of healthcare. However, the use of faith as a resource to achieve this aim is undermined by current practices and policy in health and social care. Contemporary healthcare treats faith as a private issue that has no place in the treatment of medical conditions. Even in the treatment of mental health conditions, where the use of belief frameworks in cognitive therapies might be considered more likely, faith beliefs do not appear to be positively exploited. The evidence suggests that such an approach to treatment appears to be far removed from what Pakistani patients can expect – adjustments to clinical practice for this population do not always offer even basic communication in the same language. Findings support the notion that most health

professionals are not adapting clinical practice to the ethnic or religious identity of Pakistani people and that they lack the skill or inclination to adequately distinguish between the two.

The data provides evidence that Pakistani people with chronic illness most often take the lead from health practitioners about what to discuss, and that they often concur with the view that healthcare contexts are irrelevant to discussion of faith beliefs. It is clear from the findings that this perception is not, however, accurate; the religious identity of Pakistani people with chronic illness can affect their communication patterns in significant and distinct ways. Nevertheless, patients adapt to healthcare contexts by making this aspect of their identity almost invisible with adverse consequences for treatment and self-care. These findings confirm that the influence of Muslim identity can not be confined to the private sphere and there is a need for European secular contexts to engage with this identity (Cesari 1998).

Where the issue of religious or ethnic identity is raised, practitioners may deny that these have the same impact on communication or self-care as other aspects of identity such as age, class or education. Religious and ethnic identity is thus denied the same status in relation to an individual's self. As has been highlighted earlier in Chapter 3, a vacuum exists in healthcare policies in respect of religion and, whilst ethnic health inequalities are acknowledged, there is little attempt to address these inequalities in policy or practice. The effect of this vacuum is to legitimise the position of those who deny status to ethnicity and religion as factors that can affect interaction between practitioners and patients.

The findings could be used to argue that deliberate attention is not paid to the religious and ethnic identity of *any* people with chronic illness in clinical settings. However, as demonstrated in Chapter 1, the idea that religious beliefs are a private aspect of identity and so not relevant to social communication is a cultural construct peculiar to the history of religion and science in Europe. Furthermore, dominant patterns of behaviour and organisation in healthcare do reflect the prevailing culture in UK society. For example, routine appointments are unlikely to be offered over Christmas or Easter, whereas the festivals of Eid are unlikely to be taken into account when appointments are offered to Muslim patients.

Dismissiveness of religious and ethnic identity in the broad thinking about communication may explain why findings show that no action was being taken to address the specific needs of Pakistani people with chronic illness in some clinical settings. Service development can only take place after an initial acknowledgement that specific needs exist and that services are lacking in terms of meeting these needs.

Through an exploration of communication in different settings and between different respondent groups, this chapter has provided the context in which Pakistani people with chronic illness learn about their condition, and how to adapt to it, from various sources following diagnosis. Findings indicate that, whilst not the only influence on communication, religious identity significantly influences communication between health practitioners and Pakistani people with chronic illness. Professional perceptions of faith identity converge to corrupt the communication process so that religious teachings can not be acknowledged as a positive resource in healthcare settings or drawn on in relation to treatment. The dynamics of such interaction in healthcare settings are reflected in other contexts and have a negative effect on the wellbeing of Pakistani people.

An understanding of how religious teachings contribute to decision-making and how they are balanced against other influences on decision-making is crucial to any assessment of the impact of religion on Pakistani people with chronic illness. As in this chapter, which highlights the influence of different aspects of identity on communication, Chapter 7 examines the various influences that may affect individual decision-making alongside each other, to assess their relative impact.

Chapter 7: Influences on Decision-Making

7.1 Introduction

The previous chapter has demonstrated that the faith identity of Pakistani people with chronic illness significantly impacts on communication with others involved in their health. This chapter considers the consequences of this for decision-making in relation to health, again taking into account other influences on the decision-making process. The views and experiences of research participants in relation to the decision-making process were explored in a number of ways during the course of this research. During semi-structured interviews patient narratives often revealed the influence of others on their decisions as well as the importance they attached to their own judgement and personal experience. Fieldwork also provided opportunities to observe influences on patient and professional decision-making, for example whilst attending clinic appointments with patients or shadowing health practitioners.

However, the most revealing data about influences on decision-making was gathered from people with chronic illness during third interviews, using a participatory research method (see Chapter 5). This method enabled me to formulate a hierarchy of influences for each participant - which could be compared across the sample. It also enabled discussion of the reasons for particular choices and of the interplay between religious and other influences. The findings from this exercise are presented in the following section.

7.2 Results of participatory exercise

A comparison of different influences across the patient sample drawn from this participatory exercise is given in Table 4. The table shows that a variety of influences contributed to patient decision-making about health and treatment. Advice from health professionals was most often balanced alongside personal judgement and external influences such as family members, media programmes and health literature.

The number of influences selected by respondents varied, however for most of the sample, between four and seven influences were significant. Respondents often chose to give equal value to different influences: most commonly, GP influence was balanced alongside personal judgement and these were given the same position in the patient's hierarchy. There was a clear gender difference, however, in the number of influences on decision-

making about health. Five of the ten men in the final sample considered only themselves and their GP had any influence over these decisions, whereas women in the sample chose at least four different influences. This is perhaps a reflection of access to and interest in these other influences; for instance, women were more involved in community groups than men and more likely to mention TV and radio programmes about health.

Table 4: Influences on decision-making about health

	1 st choice	2 nd choice	3 rd choice	4 th choice	5 th choice	6 th choice	TOTAL	Specific rejection	Weighted score ³⁶
Self	11	6	3	-	-	-	20	-	108
GP	6	7	5	1	-	-	19	-	92
Hospital Dr	4	5	4	-	-	-	13	1	64
Religion	4	3	1	1	2	-	11	2	49
Family	0	4	4	2	-	-	10	1	41
Other health professionals	1	2	1	1	1	-	6	3	22
Friends/ community groups/TV and radio	-	1	1	2	-	2	6	9	8
Literature	-	-	1	1	2	-	4	4	7
TOTAL	28	28	20	8	5	2	89	20	

The results shown in this table are combined with data from semi-structured interviews and other fieldwork activity about each of the influences highlighted and explored in detail below. In order to present the findings coherently some of the influences in the table are grouped and discussed under the same heading.

³⁶ Weighted scores for each choice are calculated by allocating a score for the column multiplied by the number of choices within it. Scores range from 6 for each 1st choice to 1 for each 6th choice. Specific rejections are scored negatively.

7.3 Personal judgement and values

This section explores the choice of 'self' and 'religion' in Table 4. An individual's own judgement was an important factor in decision-making about treatment – everyone in the final sample stated that this would have some level of influence on their own decisions about treatment. Most people gave their own decisions a prime or secondary place in terms of influence.

People with little formal education beyond primary level³⁷ were more likely to rate their personal judgement after the advice of their GP or hospital doctor. Exceptions in this respect were people who had had negative experiences with health professionals, who were more likely to place their own judgement before that of their GP or hospital doctor. The support of a family member who was able to interpret and advocate on their behalf also often decreased professional influence and increased reliance on personal judgement and on this carer. A relationship of trust and the ability to access additional sources of support and advice thus appears to be related to the extent of an individual's reliance on his or her GP.

Respondent narratives revealed that other influences on decision-making were usually mediated by personal experience and judgement. Thus advice from practitioners or family members, even if acknowledged as correct, was often only followed if considered manageable either in the short or long term. Advice on dietary changes, as highlighted in Chapter 6 (and later in this chapter), was most commonly mediated by patients through what was acceptable to them (in terms of normal diet, taste and health beliefs about diet) and what was possible in the context of family dynamics. Advice that did not take account of the context of an individual's life was often disregarded. Although dieticians felt the advice they gave Pakistani patients was culturally appropriate, a number of people with chronic illness said they had been advised by health professionals to eat bread or sandwiches at some mealtimes. According to the health beliefs of these patients, bread had a bloating effect on the body and did not provide the energy they felt they needed from their diet. These beliefs contradicted and therefore lessened the influence of this advice.

³⁷ approximately age 11

Personal judgement about health decisions was based both on the values and beliefs of patients as well as on their experience. Religion was an important value framework and influenced the health decisions of over half the final sample, with a prime or secondary level of influence for a third of patients. Religious values were important at a personal level and could set the boundaries for what decisions could or should be made. The strength of these convictions was often expressed very strongly:

My views can never be changed regarding the religion. They can be improved, that is what we hope for from Allah
(CT - male with pericarditis and depression)

The centrality of this influence varied considerably even within the group of patients for whom religion was a significant influence on decision-making. The data suggests that for respondents who accorded religion a prime position, these beliefs and teachings came prior to and determined their own judgement in all areas. In such instances, religious teachings had more authority than any other influence on decision-making. For other respondents religion had a more advisory role and was often grouped with the influence of family members, health professionals and friends.

The influence of religion on decision-making was felt by some respondents to be compromised by an ambivalent relationship between faith and action, so that, although an individual might know that religious teachings should be of the highest priority, other concerns distracted him or her from following this knowledge through with related action:

Q: [The influence of] religion, is this more than the doctor, less or equivalent?

A: More I think if you believe in it, but we don't believe in it [properly]

Q: What do you mean that you don't believe?

A: It's like we will be reading [prayers or the Qur'an] but the concentration is elsewhere

(HX - female patient with diabetes)

As noted in the previous chapter, some respondents felt that their religious practice was a 'private' matter rather than one they should discuss with health practitioners. Those who specifically rejected religion as an influence on health decision-making felt there was no

connection between religious teachings and health, although religion did influence other areas of their life. Practitioners often appeared to share and reinforce this view; instances in which religious practices or beliefs affecting self-care were raised by people with chronic illness generally drew non-committal responses that left this kind of decision-making to patients' own judgement. This reluctance to discuss religious practices, along with other dynamics affecting the role of physicians in decision-making is considered in more detail below.

7.4 The influence of GPs and doctors in secondary care

General practitioners were influential for almost all patients in the sample. The single exception was a patient who had a range of chronic conditions and who had developed more familiarity with her doctors in secondary care as a result. Her most recent diagnosis had been made in secondary care and one doctor in particular had taken on overall co-ordination of her healthcare. Her choice therefore showed consistency with other people - the role of co-ordinating health services and referring patients for further treatment was one of the reasons other respondents gave for considering GPs to be more influential than doctors in secondary care. The overview of their healthcare this gave GPs meant that individuals would often clarify advice given in secondary care with their family doctor.

People with chronic illness valued the specialist knowledge of doctors and their ability to carry out diagnostic tests, which were seen as 'giving an insight into the illness'. Some patients showed clear deference to doctors, especially for health concerns which they considered serious. However, interview data showed that even those who gave a primary place to GP advice in their hierarchy of influences, balanced this against their own experience in practice and would go back to negotiate changes in treatment if medication or advice was ineffective.

The long-term relationship between individuals with chronic illness and GPs was an important element in the high level of influence these physicians could command. GPs were seen more frequently and had more personal knowledge of people in their care than other health professionals. This knowledge sometimes extended to the family context, which might be taken into account during treatment. This relationship with the whole family worked both ways and recommendations by family members could also influence a person's choice of GP.

People with chronic illness felt there was more limited opportunity to build relationships with doctors in secondary care and, related to this, often felt a lack of engagement by these practitioners. This explains why, even though hospital-based physicians were mentioned by the majority of people as influential in their decision-making, only half the patient sample gave them a prime or secondary place in relation to other influences.

Individuals differentiated between the influence of doctors who engaged with them, by checking them thoroughly, asking questions, and giving personalised attention, and those who 'want to get rid of you' and 'do their duty'. Engagement was also defined as 'giving encouragement', having a 'caring' attitude and acting on behalf of the patient.

The main area in which physicians and other health professionals sought influence with patients was in disease management, and professional narratives showed that negotiation was considered the process by which such influence would be exercised:

'We offer advice and the patient can communicate back to us whether they agree with that advice or not and what they feel about complying with it. So I feel, you know, in modern medicine the job is not to give orders, the job is to negotiate, and it just makes it slightly harder if it's difficult to negotiate with patients.'

(Diabetes consultant)

Practitioner theories about why some Pakistani people might be less influenced by professional advice than others differed widely from the reasons suggested by this study. These theories most often centred on an individual's attitude or behaviour such as "not treating themselves or their health seriously", "not engaging" with their health, "not wanting advice" or feeling the advice was not significant to them. Being "cut off" through language or social isolation was also seen as a possible reason why some individuals might find it difficult to achieve the changes advised by professionals.

Apart from linguistic barriers to communication, the findings suggest that none of these reasons hold true for Pakistani people with chronic illness and that the influence of physicians is most often decreased because of difficulties in the negotiation process. Analysis revealed that the problems with communication, highlighted in Chapter 6, resulted

in problems with concordance - the kind of discussion which could lead to negotiated treatment between patients and professionals. This process was hampered in interactions by three barriers, two of which bore a significant relationship to religious beliefs:

- a) linguistic differences
- b) professionals' assumptions about the culture³⁸ of Pakistani patients, and
- c) unwillingness on the part of both patients and professionals to discuss cultural influences on decision-making if they had little common ground in this area.

These barriers to effective negotiation meant that people with chronic illness and professionals were unable to come to a shared understanding of issues that might stand in the way of acting upon professional advice, or to discuss how these issues might be addressed. This shared understanding was vital to concordance and its relationship to the three barriers highlighted is considered in more detail below.

7.4.1 Shared understanding and concordance

The three barriers outlined above hampered achievement of a shared understanding of effective treatment in a number of ways. Most obviously, as recognised by practitioners themselves (though usually not addressed in practice), linguistic barriers to communication precluded the kind of discussion that would be necessary for negotiation. These have been discussed in detail in the previous chapter and are also picked up at the end of this section. However, more complex dynamics were also at play in both primary and secondary care in relation to achieving concordance.

There was evidence that people with chronic illness generally adhered to GP instructions regarding medication following a new diagnosis. Deviation appeared to be temporary or unwitting unless there were specific reasons not to follow advice, such as not taking medication that left one feeling too drowsy to look after young children. Patient and professional accounts also both revealed a common aim of protecting long-term health and wellbeing and there was no evidence to support the theory that some Pakistani people did not take their health seriously.

³⁸ This concept is discussed in detail in Chapter 1

However, the findings revealed that people with chronic illness sometimes understood the relationship between medication and long-term health differently to doctors. Individuals showed resistance to beginning a lifelong course of treatment because of concerns about the implications for long-term health. Fears about long-term dependence were related to concerns about ‘addiction’ to treatment. Side effects such as dizziness, itching, dryness and weight gain reinforced concerns that medicines might do more harm than good in the long term. This was particularly the case where patients were being treated for multiple conditions and taking several different medicines. These concerns were sometimes reinforced by the views of family and friends. Furthermore, people with chronic illness and carers held a shared understanding that increased medication indicated deterioration in health whereas reduced medication meant improvements in health.

Professional advice could reinforce these fears and be interpreted as confirming a link between medication and increased risk to long-term wellbeing through addiction:

‘He told me that “Once you go on the tablets, you won’t be able to come off. ...So you’ll be addicted to them, you won’t be able to come off”. So I said “Look, I don’t want to take them then. Give me another way of doing it. What’s the other way round it?” And he told me to “Do some exercise and get yourself a strict diet. And let’s see if you can get some weight down, and if your health improves, fair enough - you don’t have to take them. But if then things don’t happen then I’m afraid you’ll have to take the tablets then”.’

(LI - male with diabetes)

This patient, a fluent English speaker, associated lifelong medication with addiction – he understood the doctor’s response to this concern to imply that lifestyle change was an alternative to medication. This understanding was shared by a number of people with chronic illness; improvements in diet and exercise were seen as an *alternative* to medication rather than part of an overall response to the diagnosis of chronic conditions. Medication was therefore sometimes missed and restarted only when dietary and other lifestyle changes, such as living abroad, proved ineffective. Differences in lay-professional understanding could thus lead to irregular use of medication by people who did not necessarily believe they were contravening their doctor’s advice.

'When I'm in Pakistan I take half my usual medication. I leave half. I don't take the water tablets there because I perspire. I keep taking the heart medicine. I just take the two tablets.... It does make a little difference after a few days but then I'll take the medicine again for a few days and then leave it again for a few days.'

(NE - male with asthma, hypertension, coronary heart disease and arthritis)

This mismatch in understanding between people with chronic illness and physicians appears to be related to dominant health beliefs about medication in the Pakistani community that are not being addressed by practitioners. Evidence from other studies suggests that these health beliefs may be common to patients in the general population and that the real issue may relate more to differences in lay and professional health beliefs (Stevenson et al 2000; Lambert and Sevak 1996). However, findings from this study suggest that the ability of professionals to engage with Pakistani individuals in order to address differences in perspective is far less well developed than with white patients:

'We could have a conversation about communication difficulties with white patients and we would be probably talking on a slightly different level. We would talk about issues of understanding of risk, you know conceptualising risk about how you encourage people to take tablets now to prevent problems in the future when we talk about white populations. Now clearly those factors which are sort of at a higher level of, you know, communication, those factors will equally apply in the Pakistani and Bangladeshi and other communities but we've just not got to that level.'

(Diabetes Consultant)

This block to negotiation about disease management appears to result from unwillingness by both professionals and Pakistani people with chronic illness to discuss cultural influences on decision-making. Practitioners' limited knowledge of the culture of Pakistani people could combine with patient reluctance to initiate discussion so that the context in which patients made decisions was not taken into account during communication about treatment.

Decision-making about medication whilst abroad or during Ramadan was highlighted as a particular issue on which practitioner awareness needed to be raised. Although many respondents juggled medication to allow them to fast during daylight hours, individuals were generally comfortable about missing fasts where they felt this would entail too much physical discomfort. In such cases they would take advantage of scriptural injunctions to give charity as an alternative to fasting (The Qur'an 2:184)³⁹. Where practitioner support was requested in order to make this kind of decision, however, it was not always offered. NE, experienced considerable pain and a fever because he continued with his fast rather than breaking it in order to take medication for arthritis. He had consulted his doctor beforehand about whether or not to fast and had been advised to 'look after his health'. This vague advice left the process of decision-making entirely with NE. Either because he was unaware of the option to give charity or because he lacked the legitimacy he needed, NE felt he had to fast.

This situation raises the question of how far training for health professionals should address the religious beliefs of patients. At present it appears that professional knowledge of religious practices is too limited to allow health practitioners to draw on these as a way of giving useful advice to patients. The health professionals observed during our fieldwork felt their role was to advise rather than dictate how individuals should manage their condition. However, effective advice requires knowledge of the context in which patients live. For example, a white patient attending cardiac rehabilitation was advised not to mow his lawn when it had become very overgrown and to mow twice over the summer to exert less energy at one time. The difference between this advice and that given to NE was that the doctor's lack of knowledge of the options available in relation to fasting meant that no alternative could be presented to NE, who had only his own resources to fall back on. The fact that he had consulted his doctor suggests that, given a clear indication that fasting was not recommended, he may have felt that missing the fasts was legitimate (see earlier discussion of the need for legitimacy in Chapter 6). It could be argued that, just as knowing something about lawn mowers helped in the scenario described above, a health professional who knows something about the religious practice of Muslims is likely to guide the decisions of a Muslim patient more effectively than one who is uninformed about this area of a patient's life.

³⁹ see Pickthall 2000

Its relation to concordance with medical advice, the balance between religious practice and medication could sometimes be delicate but was not seen as a conflicting relationship by respondents with chronic illness. Prayers for better health did not preclude taking medication and in practice most respondents appeared to agree with CT that 'prayer and medicine go hand in hand'. Even where respondents rejected medical advice in favour of a decision to prioritise religious observance, as in the instances of fasting mentioned above, this was not usually continued when adverse physical symptoms were experienced. For many respondents, this decision was an experiment in whether they could manage to fast or ought to take advantage of the alternative options that exist within Islam for those who are ill. Participation in an annual event which enhanced spiritual awareness and increased community cohesion was not something patients gave up lightly, particularly because of the heightened awareness of mortality which chronic illness inspired. These understandings were also reflected in ideas about fate, explored below.

7.4.2 Understanding fate and fatalism

Most respondents accepted their illness as part of their destiny and interpreted this experience as a test of their patience, or (more rarely) a punishment for past misdeeds. However, this position risked misinterpretation by health professionals. Individuals sometimes expressed their belief in ways that could be interpreted as fatalism; when asked about his expectations for the future, NC for example said that this was in God's hands, 'A person can't do anything'. Mrs N similarly fasted in Ramadan saying 'If my health is meant to become worse then let it, it doesn't matter'. At the same time, both respondents were taking regular medication, paid attention to any deterioration in their symptoms and respected the advice they had been given by health professionals. Such statements could however be taken at face-value and out of context by health professionals. Religious justifications that were used to support an individual's decision on treatment could be understood in isolation and could prevent health practitioners from considering other reasons why a Pakistani person might resist certain forms of treatment.

As highlighted in Chapter 6, religious views about destiny and accepting one's fate may be used as back-up reasons for decisions that are driven by other beliefs about health. Dr M, a diabetes consultant, recognised that refusal to accept insulin injections was likely to be driven by fears about what they symbolise in terms of the progression of diabetes:

'I think we're just starting to understand you know, this huge resistance to going on to insulin because it then means that they've got a more malignant form of diabetes which they don't accept at that stage.'

(Diabetes consultant)

Developing a shared understanding at this level was far more complex than attributing decisions to an area such as religion or culture, which health professionals could treat as a personal arena. Pakistani patients who felt strongly that they did not wish to begin 'injections for life' may, indeed, be using this 'hands off' approach to religion as a way of *preventing* health practitioners from attempting further persuasion. As with Mrs N above, this line of argument might be used to head off a discussion where respondents had already made up their mind on a course of action and did not want to be dissuaded.

Poor understanding of the health beliefs of Pakistani patients appeared to present a block to health professionals entering into any dialogue of negotiation. The absence of this dialogue was clearly detrimental to individuals with chronic illness who consequently had more limited input from professionals in decision-making than people from the ethnic majority.

A variety of reasons for lack of engagement in such decision-making appears to exist. Whereas with white patients efforts were being made to develop a shared understanding of health beliefs, practitioners did not feel confident about discussing the health beliefs of Pakistani patients if they had limited knowledge of their cultural context. Patients were often equally unwilling, sometimes assuming professionals who did not share these values would either undermine or dismiss their concerns or wouldn't understand the influence of religion on their experience:

'Fasting and prayer do not concern the doctors... They don't even know what it is.'

(NC - male patient with coronary heart disease)

This lack of confidence on both sides presented a block to shared understanding of how patient beliefs affected decisions about treatment. Given the significance of shared

understanding, however, and the high influence religion had on decision-making, the findings suggest that these are precisely the areas in which practitioners need to develop dialogue and understanding with Pakistani patients. This type of engagement is in fact no different to discussing lay health beliefs with white patients.

Findings from this study support the argument that practitioners who are equipped to engage with patients' cultural context are more likely to develop relationships in which concordance can be developed and better health outcomes achieved. Given that religious beliefs influenced a significant number of respondents in this study and was very important for most of these individuals, exploring the impact of this particular sphere on the self-care of Pakistani individuals is likely to improve professional practice.

For example, fieldwork observation suggested that secondary clinic appointments could have been better exploited to identify problems with poor management by Pakistani people with chronic illness before these led to increased symptoms. Questions by professionals about how well a patient felt were not sufficient to initiate this kind of discussion; more specific questions about whether patients were taking medication regularly or if there were any times when they did not follow advice, might reveal far more that would be useful for physicians to know and address. Even where cultural background was shared, findings suggest that discussion about religious influences on decision-making may need to be initiated by physicians, particularly if a relationship is not well-developed.

The absence of such dialogue is clearly detrimental to concordance - patient concerns about incorporating treatment into daily life, or specific times when concordance is at risk (in the sample, when individuals travelled abroad or during the month of Ramadan) were not addressed. This failure to address the beliefs and practices of Pakistani patients left them at higher risk of complications and thus sustained inequalities in health.

Where cultural practices *were* discussed it was possible for patients and professionals to achieve a shared understanding about how to manage medication or diet differently to accommodate faith requirements such as fasting and prayer - considered by some respondents to be no less important than the maintenance of physical health. This did not necessarily mean that individuals would discontinue use of their personal judgement or that concordance would be immediately achieved.

Many individuals, for example, felt that they, rather than doctors or family members, should have the final say about whether or not they should fast. TuC, the only person in the sample who was told directly by her doctor not to fast because she was too weak, went against this advice on one occasion. Her adverse physical reaction, however, reinforced the doctor's and her own family's advice and the combination of these three influences made her decide not to continue with other fasts. The GP's input into this decision and his awareness that TuC wanted to fast are clearly relevant to how far shared decision-making could be achieved between them. Even if TuC had continued to fast, follow up consultations could have taken this into account and his advice adapted or reinforced accordingly. Without any discussion of fasting, as in the case of NE, mentioned earlier, the possibility of achieving shared decision-making about this issue would not exist at all.

Most commonly, relationships were often not developed enough for patients to initiate, or physicians to participate, in this kind of discussion. Decisions about treatment that involved reference to religious practices were therefore left entirely to patients' own judgements. The reasons for these poor relationships between health professionals and Pakistani people are placed in the broader social context of life in the UK and explored further in the next chapter. It is worth noting here, however, that during consultations, the dominance of a European perspective on religion (ie that religion is a private matter) and the dynamics of who should lead discussion, relate clearly to issues of power, an important aspect of context, raised in the previous chapter.

7.4.3 Other barriers to engagement

Both patient and professional accounts showed that the organisation of secondary care could severely restrict the ability to form relationships in which shared understanding could develop. This was largely because patients saw a different doctor whenever they went, each with their own understanding of appropriate treatment. The ability to develop a shared understanding of disease management was clearly hampered by this situation and there is an implication in such arrangements that patient understanding of the condition is secondary or dispensable in terms of treatment. Pakistani people with chronic illness associated physicians who followed up changes to medication, and who sought feedback from their patients, with good quality care and putting patients' interests first. Secondary clinics often fell short of this quality standard.

Within primary care, other barriers were also revealed. Prescribing medication for short periods sometimes led to gaps in treatment. The inconvenience of collecting repeat prescriptions, and the financial implications, led some patients to suspect that economic concerns influenced prescribing and the quality of care they received. Furthermore, GPs sometimes failed to issue repeat prescriptions for increased dosage prescribed in secondary care. Patients consequently returned to a lower dosage, assuming their GP and consultant had jointly decided this.

Patients associated the age, experience and seniority of physicians to their insight and their ability to give 'the right advice'. Consequently, those patients who felt their healthcare was being compromised by young, inexperienced practitioners, felt aggrieved if their request to be seen by a senior physician was not approved and physician influence in such cases was lower.

The findings of this study point to numerous reasons why some Pakistani people with chronic illness may develop poor management of their condition. For many professionals, however, engagement with these individuals was considered almost solely in terms of language and even at this preliminary level was not adequately addressed. (This perception that ability to engage relates solely to language is echoed in the review of health and social policy in Chapter 3 and explored further in Chapter 8). Shared language is clearly a first step to negotiating with non-English speakers; however, many of the barriers highlighted affect English-speaking patients in the sample also. Steps to improve management of chronic illness within the Pakistani community therefore need to address the range of impediments and not focus solely on language. However, the need for this broader approach and for relevant training was often not recognised by practitioners:

A: I mean, I'm not sure there's a huge body of knowledge available to us about how we should handle, and in the end we end up getting what I'm giving you, which is one person's interpretation, which may or may not be valid.

Q: What would you like in terms of training? What do you think would fulfil your needs as a consultant?

A: I don't ... well, I mean ... I think probably I'd be much more pragmatic and practical about it and say that what we need is easy and quick access to translation facilities.

(Diabetes Consultant)

7.5 The influence of other hospital staff

Contact with specialist health professionals other than doctors was not routine in secondary care clinics after an initial visit and this may explain the relatively low influence of other hospital staff. On first referral, dietary advice was provided by dieticians in the diabetic clinic and by nurses in cardiac clinics. Advice appeared to be very similar in both cases although dieticians had training in culturally appropriate diets which nurses did not have. Most people with chronic illness were already aware of 'healthy eating' messages which were commonly promoted through a range of channels within the fieldwork area. Individuals appeared to retain a substantial amount of this knowledge which was given orally and backed up with literature, some of which was in Urdu.

Although many people accepted dietary advice as sound, some complained that the emphasis on what not to eat was such that it became difficult to eat anything. For such individuals the difference between their existing and recommended diet was too great to negotiate in one stage. Dieticians' practice was to focus on three or four changes in diet but other health professionals did not necessarily take this approach and in practice individuals were often given advice which they felt was unmanageable because recommended diets bore little relation to their normal diet or to their health beliefs about food.

Findings show that religion, ethnicity and other influences had a significant impact on these beliefs. Religious teachings set the boundaries for what foods were allowed (*halal*) and forbidden (*haram*). Within these boundaries, ethnic traditions and regional or class variations, could also affect food choices. For example, many respondents talked about

foods which had a 'hot' and 'cold' effect on the body, concepts that cannot be traced back to religious scriptures. A number of patients believed that medicine had a heating and drying effect on the body and that they needed to increase their intake of food if they were taking a lot of medication. Dieticians were aware of some of these beliefs but not about many others that Pakistani individuals mentioned in interviews. Consequently there was no exploration of ways in which these beliefs could be accommodated by professional advice.

Dieticians were aware, for instance, that sugary drinks were considered important for energy by a number of diabetic patients. These professionals felt frustrated that patients 'wouldn't believe' that these drinks were damaging to health but discussion about other 'energy' foods that might have been an acceptable replacement did not take place. Negotiation about disease management appeared to focus around why patients were not following professional advice rather than how this advice could be adapted to fit in with an individual's own beliefs about diet. This suggests that the lessons for developing shared understanding and negotiating self-care outlined earlier need to be addressed by all health professionals involved in chronic illness management and not just by physicians.

As mentioned, most newly diagnosed patients did not usually see a health professional other than their GP or doctor in secondary care after their initial briefing on diet and self-care. Specialist nurses in the diabetic and cardiac rehabilitation clinics recognised that the amount of oral and written information which patients were given at these briefings was very demanding and not organised in ways that best suited patients. Fieldwork observation highlighted the general nature of advice, and that adapting this advice to one's own experience appeared to be left to the individual with chronic illness.

For example, a cardiac nurse's general advice about the effects of 'bursts of energy' on the heart was then related by a white patient to an example from his own experience when he had felt breathless after climbing a ladder into the loft. The same individual was also advised to stop 'binge drinking' completely, a sudden and major change which had consequences for his social life. The barrier to making these changes - being derided by his friends - was again left to the patient to negotiate - and there seemed to be no middle ground between his previous lifestyle and that promoted by the nurse. The context of decision-making was not therefore always addressed in the professional advice given and

professionals appeared to locate decision-making almost wholly in patients' individual behaviour whilst underestimating the importance of social support.

In the sample, there was evidence that people with chronic illness were very sensitive to context, particularly in relation to diet, as highlighted in Chapter 6. Despite concern about the long-term effects on health, family and social support for medication was generally strong, with the exception of medication for depression. In relation to diet, however, a number of forces worked against professional advice at both a personal and social level. Not only did patients sometimes have to abandon strong personal preferences for food, but other dynamics, such as how family meals should be organised or social expectations in relation to hospitality, also had to be negotiated. Family and social support, combined with an individual's own response to the new identity imposed upon them by chronic illness, could act as enablers or barriers to change. Most patients took a pragmatic approach and followed professional advice when this support was strong and they felt able to negotiate these barriers. Other ways in which family members influenced the decision-making of people with chronic illness are explored in the following section.

7.6 The influence of family members

Families were influential in patient decision-making although they never had first place in individual hierarchies of influence and advice from family members was always mediated through personal judgement and experience. Family members who supported patients to manage their condition or attend appointments (mostly daughters or husbands) were usually most influential. The influence of those who had an interpreting role was significant and often equal or greater to that of doctors.

Respondent narratives showed that relationships with health professionals were not always discussed with carers, who were often vague or unaware about what their relatives thought of the care they received. Carers sometimes assumed that their own views about professionals or about treatment were shared by patients. However these views, if shared, were not always expressed by patients and might not have been held as strongly. UC's husband, for example, felt that some of her treatment in secondary care was disjointed and that her questions were not adequately answered. UC had made none of these complaints in her own interview. She was influenced heavily by her husband, whom she rated above her GP, in decision-making about health. It is likely, given the finding that carers often

influence the kind of communication that takes place with practitioners (see Chapter 6), that his views would be expressed more strongly during consultations. This again supports the argument for direct communication between people with chronic illness and professionals made in the previous chapter.

Apart from providing language support, family members played a significant role in explaining and reinforcing professional advice, as well as advocating for their relative. However, people with chronic illness sometimes felt that carers were involved to a greater level than themselves in discussions with health professionals. The amount of information that was passed on to them by carers was sometimes coloured by relatives' wishes to reassure and was much more limited than patients felt they needed. Direct communication with knowledgeable health professionals in their own language was therefore greatly valued when it was available as this enhanced an individual's ability to make informed decisions:

R: There was an Indian nurse who asked me if I knew what I had come for. I told her that I had come for an x ray but I didn't know how it was to be done. She then went on to explain everything in my own language, all of which I understood ... I learnt more from her. My daughter S knew what was happening and she would tell me but I didn't register it as much as when the nurse told me ... I mean she told me about every single thing openly, they didn't tell me openly, they said there was a suspicion ... Like 'Mum, there's nothing, they just suspect there might be this' She [the nurse] told me about the suspicion properly 'These are the things, this is what they suspect, it could be this'.

I: What's the better approach?

R: The better approach is that I had a complete understanding.

(TuC - female with hypertension and undiagnosed stomach pains)

Family dynamics sometimes adversely influenced an individual's ability to follow professional advice. As highlighted a number of times already, this particularly affected changes to diet, which required the support of other members of the household or relations. Male patients appeared to have less control over this aspect of decision-making because they were less involved in preparing family meals and consequently had less control over their content. In most of the households included in the study, women took

specific responsibility for preparing meals. Husbands might help out when their wives were ill, however preparation of meals was not seen as an area of conflict except where women failed to adopt their husbands' advice on 'healthy eating' practices. People with chronic illness generally valued the monitoring of their diet by members of their household (although this could sometimes cross the boundaries patients felt were appropriate in their relationships) and complained if the rest of the family did not make changes to accommodate or prioritise their dietary needs.

Involving family members in chronic illness management was important because of the support they could offer in such situations, but approaches to this were not consistent across different clinics in the same hospital. The cardiology unit purposely involved family members in discussion of chronic illness management whereas the diabetic clinic only involved members who happened to accompany relatives to hospital. Considering the significant influence family members sometimes had over an individual's ability to follow professional advice, especially in relation to diet, there appears to be a need for more consistency in this respect to support patients' efforts to incorporate recommended changes.

The influence of family members on patient decision-making was considered by one professional to be related to extended family living and levels of education. She believed this influence would decrease in the next generation as more people lived in nuclear families and had higher levels of education. The data supports this observation to some extent but not entirely. Carers who could speak English and support non-English speaking patients had most influence on their decisions, whether or not they were living in the same household, whereas English speaking patients did not rely on family members for advocacy or explanations. However, in relation to diet, both in nuclear and extended families and whether or not patients spoke English, members of the household had a clear influence on patients' motivation and ability to follow professional advice. Where this advice was not reinforced or monitored by family members, patients identified their ability to follow dietary recommendations as a problem.

7.7 Other sources of influence

This category in Table 4 (see above) combines findings for friends, literature, community groups, radio and TV programmes and, in one case, other professionals. The influence of

advice from these sources was often grouped together by patients and ranked alongside other influences rather than seen as having inherent authority. Significant findings relating to some of these sources of influence are discussed in more detail below and their relationship to religious beliefs and other aspects of culture is discussed.

7.7.1 The influence of friends

Friends and community members were often considered unqualified to give advice about treatment unless they had personal experience of a condition. Even then not all patients considered lay advice to be reliable. Although only one person in the sample felt her friends were influential in her decision-making on health, data from qualitative interviews shows that friends often provided information about alternative medicine that patients had tried. Dietary changes and herbal mixes were sometimes recommended in this way and even brought back from Pakistan. Although there were some accounts of fraudulent healers, patients generally felt these alternative remedies would not have harmful effects and were happy to try them for a short time to assess their impact. This was usually not discussed with physicians, either because these remedies were not considered harmful or because of the barriers to discussing cultural influences on health discussed previously in this section.

A number of Pakistani people also mentioned the difficulty of refusing unsuitable food at social occasions, which was often pressed upon them by friends and relatives who might be aware of dietary recommendations but more attentive to their responsibilities as hosts. Religious teachings promote honouring one's guest (see Khan 1987)⁴⁰ and this is interpreted within the Pakistani community to include offering rich foods, such as kebabs and samosas, which are often fried and made with red meat, and sweet dishes that contain a good deal of sugar. All these types of food are strictly limited in healthy eating advice and social visiting can thus present considerable dilemmas for people with chronic illness.

Changes in the traditional expectations of hosts and guests in these situations require social legitimacy. Evidence from the study suggested that health promotion activities within the Pakistani community could help to address these community-level expectations by raising awareness and legitimising refusal of foods that were not recommended by professionals.

⁴⁰ Hadith: Volume 8, Book 73, Number 47

Raised awareness could, perhaps, also encourage hosts to offer foods that accorded with professional advice, such as fruit and nuts, as an alternative to people with diabetes. Health promotion activities around diet were, however, usually aimed at the community as a whole and not linked to awareness of the problems faced by some people with chronic illness. Findings suggest that highlighting ways in which the dietary needs of people with chronic illness could be accommodated in social situations might support individual efforts to observe healthy eating advice that would otherwise fail.

7.7.2 Literature

Comprehensive literature about diabetes and coronary heart disease was given to a number of patients in the sample. The four patients who were influenced by literature about health were primarily influenced by their own judgement or religious beliefs. Professional advice, whether written or oral was therefore seen as a support to their own judgement and mediated by their own experience and values.

In common with community activities in health promotion (see below), and TV or radio programmes, leaflets were considered by those who read them as 'good for general knowledge' but not able to address the specific questions that might arise in relation to individual experience of a condition. Information was recognised as being more detailed in written form; one patient, for example, had learnt about cholesterol from leaflets but this had not been mentioned in oral advice. Initiatives suggested by Pakistani key informants (professionals working within Pakistani communities) such as materials in Urdu or a web page aimed at Muslims, do not appear to be supported by these findings as the prime way in which resources should be used. Whilst these may have their place alongside a range of other strategies for prevention, general information does not appear to be considered the most necessary form of information by people already diagnosed with a chronic illness. In any case, lack of literacy would be a bar for many patients and no patients in the sample mentioned use of the internet to access health information, even though internet facilities may have been available within the home. Access to reliable advice from qualified staff was considered far more useful in terms of building up knowledge of self-care (see 'Community organisations' below).

Half of both the initial and final sample of patients had not been educated beyond primary level⁴¹ and therefore relied on others to read literature for them, even when this was in Urdu. Patients did not always ask for this support and depended instead on oral advice which they sought when they needed to know how to deal with particular problems. Despite the difference in education and access to literature, some health professionals sought advice and information in the same way, seeking oral guidance from colleagues on specific issues to which they needed to respond. A cardiac rehabilitation nurse, for example, described how knowledge was passed on in this way in the clinic in which she worked:

‘There’s a lot of consultation [between staff] every day, every minute of the day, “What do you think about this? What do you think about that?” on a lot of aspects of what we do. And until a situation happens, “Oh I never thought about ... How do we actually deal with that problem?”’

Continuous access to reliable guidance was thus an important means of developing knowledge for people in both these respondent groups but this was not available to either patients or to professionals in relation to the specific needs of Pakistani patients.

The evidence showed that GPs constituted the main source of such guidance for most patients and policy initiatives such as the Patient Advice and Liaison Service (PALS) or ‘The Expert Patient’ training courses had made little or no impact on people in the fieldwork area. No system of referral existed to enable or encourage patients to contact other health workers to increase knowledge of their condition. In relation to health promotion activities, community-based staff could play a role in raising general awareness of disease management, however they were often not clinically trained or equipped to answer specific queries and did not target their activities at people with chronic illness (see ‘Community Organisations’ below).

Consequently, people with chronic illness could sometimes delay decisions if they had any doubts about their treatment or self-care and needed specific guidance. A number of patients mentioned waiting until their next appointment in primary or secondary care to access this guidance and this could delay decisions for weeks or even months. The

⁴¹ approximately age 11

evidence suggests that increased access to reliable advice between appointments would help avoid gaps in treatment and aid patients to develop their specific knowledge in relation to self-care.

Health professionals suffered from a similar lack of reliable guidance in relation to providing healthcare to Pakistani patients. Oral transmission of knowledge between practitioners in clinics could not address this deficit if knowledge of Pakistani patients was limited within the staff group, and could even help to promote stereotypes. Expertise about the healthcare needs of Pakistani patients was located in community-based activities which were partly or completely funded by the Health Authority, however, no use of this expertise was being made within mainstream provision to develop more sensitive and appropriate healthcare. The lack of formal links between community-based health education staff, voluntary organisations and mainstream services showed poor use of resources to address inequalities in health. This issue and the role of community organisations generally, is discussed further below.

7.7.3 Community organisations

The table reveals the relatively low influence of community organisations on decision-making and this can be explained with reference to findings from other fieldwork data. The majority of the sample used community organisations to provide support in their dealings with institutions such as the DSS, housing and tax offices and fuel suppliers. Community organisations were rated according to how well they were able to advocate in these situations and how accessible they were to local people. Many of the sample considered this kind of support to be important for their wellbeing. A number of respondents asked for help with issues related to housing and benefits when they were offered support with 'health-related issues' for this study (see Chapter 5). However, the role of these organisations in relation to health advocacy did not appear to be significant. Respondents who mentioned problems in relation to their healthcare had not thought of approaching community advice or other organisations in order to take these forward. The lack of formal links between community-based health activity and clinical health services may explain why most patients did not feel community organisations were relevant to their health.

Health promotion activities based in community settings were almost always aimed at established groups or at the general community and not at particular individuals with a specific condition. Community social groups, which were almost exclusively aimed at women, would regularly be provided with speakers whether or not the topic was of personal relevance to them. The number of social groups within the fieldwork area was small and speakers looking for audiences often contacted these established groups as a way of reaching the Pakistani community. Most people within the patient sample did not attend any of these groups and fieldwork revealed that, although considered useful knowledge by many, at least some of the members of these groups felt that speakers were so frequent as to have become an inconvenience and to interfere with the women's own reasons for attending.

This situation echoes earlier findings about the sometimes ineffective use of resources that had been made available to address the needs of Pakistani communities. Although, health promotion aimed at prevention in this community should by no means be dismissed (Rodrigo and Munton 2002) the way resources were used meant that only a very small number of people, mostly women, benefited from the information. Exploiting primary and secondary healthcare links and targeting people with chronic illness in addition to these community groups would appear to have been a more effective way of deploying these speakers and of avoiding gender bias.

Speakers at community groups gave general information on a range of chronic conditions or health issues but were usually not qualified to address the specific concerns of people within the group. For example, a question about thyroid problems was raised at a talk on diabetes in one 'Healthy Living' group. Such questions, which were important to individuals' own self-care or that of a family member, might be left unanswered because the speaker could only refer individuals to their GP, thus maintaining the limited opportunities for building up personal and specific knowledge about disease management.

A speaker's ability to adapt to the needs of a particular audience was thus an important factor in the level of influence they could have and clinical training and experience was a great advantage for this reason. Qualified nurses, doctors and dentists who gave such talks were much more able to adapt their information and suggest ways forward to patients, even though this might be coupled with advice to visit their own GP, than speakers who

had received a short training course in a specific area. Thus TuC described a large community event about coronary heart disease in which she understood nothing but was very grateful for the chance to ask the speaker, a female Pakistani GP, her own question about severe gastric pain at the end. She was so influenced by the advice to drink more water that she drank three glasses before leaving the venue.

Health Action Zone funding shaped much of the community-based activity within the fieldwork area. However, projects were often small scale and disparate, reaching a very small minority of people within the Pakistani community. None of the patient sample had been referred to a community-based group following diagnosis and only six of the original sample of 31 patients had regularly attended community-based activities. These were mostly social groups and only two individuals were part of a 'Healthy Living' group. Nevertheless, health professionals could overestimate the level of contact patients had with community organisations in relation to their self-care. A local GP, with whom six patients from the sample were registered, felt that his Pakistani patients would have regular and extensive access to health promotion activities and services within the local area:

I think they've got much support from other sources you see. They go to the day centre and day clinic here and there, the community centre and somebody comes from the community centre and checks their blood pressure. ... there's the Bangladeshi community centre ... once in a month I think some nurses come from the Health Centre and do the blood pressure check, test and a kind of medical check-up... and somebody comes from the same, I don't know the exact name of the centre, and gives advice to the ladies.

(General Practitioner)

Community fieldwork also showed that health professionals rarely made referrals to community-based groups that could offer appropriate support to people with chronic illness and there was only one primary care practice that had referred any of its patients to a voluntary organisation. Community services usually complained of a lack of response from GPs who had been contacted about the services these organisations could offer.

The lack of liaison between voluntary sector organisations and other sites of healthcare provision was worrying. Specialist services to meet the needs of South Asian communities had developed expertise in their knowledge of these needs yet no attempt was made to

make use of this knowledge for the benefit of mainstream services, where most patients were seen. Although community-based activity was partly or completely funded by the Health Authority, staff within these voluntary organisations were often managed by individuals and management groups who had little training or expertise in management and staff were also excluded from career progression and training opportunities within mainstream service. This resulted in underdeveloped skills which were often inadequate to meet the needs of service users. Experienced staff understandably moved on to posts outside the voluntary sector to be replaced by less experienced individuals who again had limited opportunities for training and skills development. Pakistani service users were disadvantaged by this lack of liaison between voluntary and mainstream services, receiving poor quality provision in both areas. The findings suggest that links in the area of staff training would benefit both sectors and, ultimately, service users.

The 'Health Educators' who appeared in the fieldwork area in 2002 suffered from both the above limitations. The initiative aimed to improve health awareness within minority ethnic communities and these individuals had been recruited from such communities. Following a 13-day training course covering first aid, heart disease, diabetes, smoking, healthy eating, stress and relaxation, the health educators contacted community groups to deliver a series of sessions about 'heart health awareness'. As previously noted, the groups contacted to deliver these sessions had mostly been organised to provide social activities for women. There appeared to be no liaison between these workers and professionals in primary care or chronic illness clinics, who could have acted as a link to newly diagnosed patients. In view of the lack of time practitioners feel they have to follow up advice, these workers could have been a valuable resource to help people who needed support and reinforcement for their self-care regimes. The health educators' own training was basic and general and their own level of skill and knowledge could therefore have benefited from greater links with clinics and supporting patients to find answers to specific questions.

The absence of links between the different sites of health activity within the fieldwork area ultimately disadvantaged people with chronic illness, whose only regular source of information about health was often their GP. The findings show that the current lack of collaboration between primary, secondary and community-based healthcare activity affects the quality of services to Pakistani patients in all settings. The evidence suggests that expertise and opportunities for training need to be shared between the different areas – to

develop more appropriate services for patients in mainstream services and to provide better management of personnel and opportunities for training and career development in voluntary sector organisations.

7.7.4 *The media*

Health information was sometimes obtained through the media, particularly satellite TV channels in Urdu or Hindi. Each of these languages indicated affiliation to Pakistani (Urdu) or Indian (Hindi) stations, though both languages were generally understood by most respondents. Respondents who had access to Urdu channels such as Prime TV or who had listened to local community radio broadcast during Ramadan particularly valued the religious element of programmes. Being able to hear the call to prayer during the day, to see people at prayer in important mosques around the world as well as broadcasts in which the Qur'an was recited or explained was mentioned as the reason for watching or listening to these channels.

Conversely, some respondents specifically rejected Hindi channels because of their anti-Muslim or anti-Pakistan slant in news bulletins or other programmes. There was sometimes hostility to English language channels for similar reasons and respondents often felt, along with the community in general, that some media reports of global events, such as American attacks on Afghanistan and Iraq or reporting of news from Israel and Palestine, could be little more than political propaganda, aimed at hiding rather than exposing truth and at deceiving the public. Thus, the framing of a particular 'message' was seen as embedded in the values of the messenger and the values portrayed by the media were often an important criterion for accepting and watching particular programmes.

Health promotion broadcasts, however, seemed to be exempt from these reservations and a number of respondents mentioned informative programmes about health on channels which at other times were perceived as hostile. In particular, the information presented in Hindi by a Sikh doctor on a weekly health programme was considered useful and helpful by Pakistani people who had access to satellite television. The broadcast appeared to be effective in raising awareness about health issues, particularly where respondents had some experience of, or interest in, a particular condition.

During the fieldwork period a number of initiatives were noted in relation to using the media for health promotion messages: videos, radio broadcasts and drama productions were effective in bringing groups of service users together to design, plan, become actively involved and highlight awareness of health concerns. However, within the sample, awareness of such media output was noticeable for its absence. One coronary heart patient mentioned a video in very vague terms and did not appear to have retained much information from it. The impact of the Indian doctor on television appeared to be far more effective in raising awareness of health issues: not only did this programme reach more people but the regularity and familiarity of a weekly broadcast rather than a one-off production appeared to be significant. No such programmes appeared to exist on land based channels however and so many respondents did not have access to such broadcasts.

In this respect television channels have become less inclusive than in the past, when a weekly programme in Urdu, covering a range of topics, was broadcast once a week⁴². This visible acceptance of non-English speaking South Asian people in UK society is perhaps needed again, not only as a channel for addressing health inequalities, which disproportionately affect non-English speakers (Nazroo 1997), but also to promote the social inclusion and general wellbeing of people within Urdu-speaking communities (see Chapter 8).

7.8 Conclusion

Findings demonstrate that the personal judgement of Pakistani people with chronic illness is the most important influence on their decision-making and this judgement is affected by beliefs and values. Religious beliefs contribute in varying degrees to decision-making about chronic illness but were influential for more than half the sample of this study and consequently cannot be ignored as a factor in the decision-making process. Religious beliefs could set the boundaries within which any decisions had to be taken and religious practices, such as fasting and prayers, could influence, for example, the way medication was taken.

⁴² Between 1965 and 1987 the BBC broadcast a weekly programme aimed specifically at South Asian communities and using predominantly Urdu speaking presenters. The change to English medium was intended to 'reflect the changing nature of the English community' according to the BBC website (www.bbc.co.uk).

The influence of ethnicity on decision-making in the sample appears to relate mainly to linguistic ability to access particular sources of information or advice, and to influences on diet. It should be remembered, however, that language and diet are both linked strongly to and influenced by values and beliefs. For example, concepts that are easily expressed in one language may be impossible to accurately convey in another (Ahmed A 2000; Lago and Thompson 1996) and dietary choices by Pakistani Muslims are influenced by the religious principles of *halaal* and *haram*⁴³ food (Surty 1995). The concepts of religion and ethnicity are therefore not always easy to disentangle. Experimenting with medicines whilst abroad may also be related to ethnic background but again, other conceptual frameworks relating to the experience of chronic illness may also be relevant. It is important, therefore, not to assume that such findings apply only to Pakistani people or those from minority ethnic communities. There is evidence, for example, that fears about the effects of long-term medication, highlighted earlier, are shared across ethnic groups and relate to lay perceptions of treatment (Stevenson et al 2000).

Findings presented in this chapter demonstrate that the level of influence others may have on the decision-making of Pakistani people with chronic illness is linked to the quality of relationships between them. The ability of physicians and other health professionals to engage with Pakistani people in the management of chronic illness is currently limited. The data suggests that it would be considerably enhanced if they were equipped with knowledge about the context in which these patients make decisions, of which religious beliefs and practices form an important part. Currently this knowledge appears to be almost absent from clinical settings. This results in a lack of confidence to engage in discussions about how religious beliefs and ethnic traditions influence management of a chronic condition. This lack of engagement is a barrier to the development of shared understanding between professionals and Pakistani patients. Consequently, concordance is less likely to be achieved and poor management of chronic illness is less likely to be detected and addressed early.

The situation is compounded by the lack of alternatives to support from GPs. Community-based assistance and advice about how to manage a chronic condition appears to reach very few people, and even fewer of those for whom it is directly relevant. The links between statutory services and these community-based organisations are

⁴³ See Glossary: Appendix 1

underdeveloped and appear to mirror those between health professionals and Pakistani people with chronic illness. At present, cultural and clinical competence are not combined in the services on offer to Pakistani people with chronic illness. Findings demonstrate that each type of expertise is located in different areas of service provision. The separation means that resources aimed at reducing health inequalities within this community are not used as effectively as they could be in either clinical or community settings. The data suggests that joint work and joint management structures between the two sectors would help avoid wasting scarce resources and enhance the quality of service provision in both areas.

As well as explicit beliefs, findings have revealed certain implicit values held by Pakistani people with chronic illness. For example, sincerity in putting patients' interests first is expected in the care provided by professionals. Expectations that family members should be supportive and feel responsible for a person who is ill are also embedded in respondent narratives. Explicit and implicit values contribute to the context in which Pakistani people with chronic illness make decisions about how to manage their condition. These values exist in families, communities and in society and have been explored in relation to chronic illness in this and the previous chapter. Chapter 8 explores these contexts in a more general way and examines the shared understandings and values that exist in relation to Islam both within and outside the Pakistani community. The wider social context throws further light on the various ways in which religious identity affects the lived experience of people within the Pakistani community. This exploration also helps to link inequalities in healthcare to broader issues relating to inequalities in health and offers further reasons why religious identity needs to be specifically recognised in social policy.

Chapter 8: Religion and Wellbeing

8.1 Introduction

The two previous chapters on findings have highlighted particular ways in which the impact of religion on the lives of Pakistani respondents was important at both a personal and social level. This chapter explores the impact of faith at both these levels in more depth by taking account of the broader social context in which Pakistani people with chronic illness lived. Findings from ethnographic fieldwork combined with respondent narratives are used to highlight the individual meanings faith held for respondents. In addition, the shared understandings that existed about Islam both within the Pakistani community and in the broader context of UK society are considered and compared. This broader context is important because, as highlighted in earlier chapters, it is likely to be reflected in the dynamics that exist in healthcare settings. The expectations and values that Pakistani people with chronic illness bring to interactions with health professionals and how these are understood in the wider UK society can thus be examined. Exploring these dynamics will, therefore, aid understanding of why inequalities in healthcare exist and, at the same time, the relationship between Muslim identity and the wider determinants of health.

The chapter begins with a description of the physical sites in which ritual worship took place in the fieldwork area, in order to offer insight into religious groupings within the community. These and other groupings are explored further in the following section about community diversity. Ensuing sections focus on shared understandings (both within and outside the Pakistani Muslim community) of the meaning of Islam. Ritual and spiritual elements of faith are explored in relation to health and illness and to their cognitive influence on members of the Pakistani community. The way Islam is interpreted by Pakistani Muslims in daily life and understood by those outside the Muslim community is also explored. The impact of these shared understandings - on individual people with chronic illness and on Muslims in general in the fieldwork area - is examined, to increase understanding of the relationship between faith and wellbeing for this social group and to point the way forward for policy and service development.

8.2 Sites of worship

Faith activity in the local community took place mostly in gendered settings, reflecting codes of behaviour between men and women outlined in the Qur'an and *Sunnah*⁴⁴. Most of the five mosques allowed access to men and women but were attended more often by men in the sample. Women sometimes attended the Friday congregational prayer but, more often, worshipped at home or attended weekly religious gatherings either in houses or in a small number of community organisations. Health was not usually directly addressed as a topic in any of these settings; however, some of the teachings referred to illness as a way of exemplifying situations in which patience should be exercised or faith might be tested, and were considered by Pakistani respondents to be relevant to living with chronic illness. SQ, for example, felt that such gatherings increased her ability to be grateful for the positive elements of her life in comparison to those who were in worse situations. Illness was most often understood as an opportunity to practice patience rather than as a punishment for misdeeds.

Women who ran these gatherings could be consulted about faith-based cures, such as reading particular prayers or verses from the Qur'an or taking remedies for which there was scriptural authority, such as honey and black seed. Generally, however, health information of most kinds from these sources was limited. Men used the mosque to perform ritual prayers rather than as a source of such information and respondents did not perceive religious gatherings as directly influencing management of their health. Nevertheless, the communal aspect of these gatherings was relevant to some respondents in relation to health. For example, NS first sought medical advice after a relative in the mosque recognised his symptoms as possibly related to diabetes. This suggests that wider community awareness of health information will be reflected in the interactions that take place in faith-based settings, even though these sites may not act as places where such information is promoted.

The idea that mosques should be used as a site for community-based health promotion was put forward by some health professionals during fieldwork and has been suggested elsewhere, along with other community-based venues, as though all community sites are appropriate for this purpose (Medical News Today 2004; Naz Project London 2002).

⁴⁴ See Glossary: Appendix 1

There was evidence, however, that this suggestion may not fit with the way mosques are perceived by those who use them for worship. Resentment and hostility was sometimes expressed, for example, at the use of mosques during national elections by local politicians to gather support for votes. Members of the congregation who had facilitated this kind of access were on one occasion publicly condemned for taking up the congregation's time in worldly matters (and by implication their own political interests) rather than allowing the community to focus on the Friday prayer.

Although the motives for political activity can be distinguished from those informing health promotion, this finding suggests that sensitivity to the purpose for which mosques are used is important and these sites may need to be differentiated from other community venues. When asked if they ever received information about health from mosques, respondents often reacted as though this was a bizarre question and referred to worship and prayer as their reasons for using mosques. The disassociation between sites of worship and health services is reinforced by the present lack of attention to faith beliefs in healthcare, highlighted in previous chapters. Despite the regular and usually large gatherings of Muslim men for Friday prayers in mosques, it is not clear that these venues are, at present, suited to health promotion and further exploration is needed of the response such a suggestion might elicit. Evidence from this study suggests that community perspectives might not currently consider religious sites to be relevant places to offer or seek healthcare and that their capacity to fulfil such a role may need to be developed before such care can effectively be offered. The current lack of statutory support for faith organisations may need to be addressed if such development is to take place (see Chapter 3). Nevertheless, partnerships between health services and mosques are being established to widen community awareness of health information (Department of Health 2004; Aspinall and Jackson 2004).

8.3 Community diversity

Within the Pakistani community, geographical and social class distinctions existing in Pakistan and often continuing in the UK were also of significance to community organisation. The term 'Pakistani' is itself misleading in relation to community membership. A number of people who considered themselves to be part of the local Pakistani Muslim community in fact originated from India and East Africa. Whilst retaining strong and separate ethnic identities, these individuals nevertheless used and

contributed to the same social networks as the majority Pakistani population because of their religious identity, which differentiated them from the majority Indian and African populations in Leeds. This provides further evidence of the primacy of religious over ethnic identity for Muslims (see Chapters 1 and 2). For the purposes of this thesis, the term 'Pakistani community' is used, therefore, to mean people who lived in the fieldwork area and benefited from the social networks that were predominantly used by the local Pakistani population.

Amongst those originating from Pakistan, members of the Mirpuri community form a majority of this population and are concentrated in the inner city areas of the city (Geaves 1995). The rural background from which many families originate and the distinct dialect of Punjabi which they speak subjects many of them to discrimination and prejudice by other members of the Pakistani community. Many of the people in the patient sample for this study were from Mirpur. Their accounts often showed recognition of the inferior position they held within the Pakistani community. The Mirpuri dialect was seen to be at the bottom of the hierarchy of languages used within the community - below English, which was most prestigious and gave access to all kinds of opportunities, and Urdu, the national language and language of higher education in Pakistan. An individual's status within and outside the community was often assessed by the kind of language he or she could command:

'It's alright for the educated people [Urdu] is their language but there is the Mirpuri dialect which they think might lower them, therefore they speak in Urdu. There was someone I saw who looked decent and respectable. I thought to myself he is either going to speak in English or Urdu but when he spoke, he spoke in the Mirpuri dialect. I was amazed.'

(IC - female with diabetes)

In addition to religious identity, divisions based on ethnicity, and community politics were evident in relation to how community members organised themselves around faith activities. Only one of the mosques in Leeds could be described as having a multicultural congregation; all of the other five mosques within the fieldwork area were very much based on shared nationality, language and creed. Thus, Bangladeshi Muslims in the fieldwork area had a different mosque to Muslims from Pakistan. The latter group had differentiated

further into mosques following different creeds. However, some Pakistani Muslims attended the multicultural mosque (set up and dominated by the Arab Muslim community in Leeds) because they felt greater affinity with the creed promoted by its *imam*⁴⁵. As will be highlighted later in this chapter, shared beliefs appeared to be more relevant once linguistic communication was possible. The study confirms suggestions in earlier research that separate organisation for faith activity on ethnic lines may be of decreasing relevance to Muslims in the UK over time (Geaves 1995).

A special effort was sometimes needed by community organisations to avoid being perceived as affiliated to any particular subsection of the community, as this would automatically restrict membership. Thus the 'healthy eating' and exercise classes organised by a community organisation and taken up by Pakistani women were initially perceived as being aligned to a particular mosque, implying that those whose loyalties lay with another mosque were excluded. The efforts of outreach workers in drawing people from all sections of the community helped to dispel this image so that the organisation was no longer perceived as 'joined at the hip' to any one religious group.

The reputation and perceived motives of these outreach workers within the various sections of the community was important in enabling access across religious and ethnic divisions:

'Relationships are important, their perceptions of why you are doing things – is it to have a big name or are you sincere? [People will] know from your actions that you are not out for personal motives or political motives. Letting personal things get in the way, you can miss out whole sections of the community. You have to get on with all people.'

(Key Informant, Community Health Worker)

Materialism and self-centred motives for working were strongly criticised by many respondents and examples were drawn from various ethnic and religious groups. Criticism was strongest in relation to those who shared Pakistani Muslim identity, where expectations were higher. These higher moral expectations were based on the notion that Muslims should be more aware of relevant scriptural injunctions, rather than the idea that only

⁴⁵ see Glossary: Appendix 1

Muslims could behave in this way. Commitment and concern for individuals was felt to be essential in any service offered to others, whether in the statutory, voluntary or commercial sector. This approach was considered a more important quality in service providers than their faith or ethnicity:

A: If I have to use a solicitor, I use this English company, because I've been to X & Co [a Pakistani solicitor] and I'm sorry to say they weren't very helpful again. All they're after is ... getting money from the government. That's all they're after, not really helping out.

Q: Do you think there's a difference between having an English doctor and a Pakistani doctor?

A: Well, so long as he's right, that's the way I look at it. As long as he does the right job, that's - whether he's a Hindu or not Muslim - so long as he does the job right, that's all that matters.

(LI - male with diabetes)

Thus assessments of motivation and sincerity were a primary influence in the criteria used to assess relationships with professionals and were more important than shared faith or ethnic identity. This concept of sincerity has strong foundations in the religious teachings of Islam, which also point to materialism and hidden motives as indicators of hypocrisy and moral deviance (Ibrahim E 1997; Yahya 2004).

Within the Pakistani community itself, certain ways of practising religion were a target of prejudice in some cases, which mirrored prejudice experienced outside the community. As mentioned earlier, Mirpuri people faced particular discrimination and stereotyping and sometimes religious and ethnic identity were combined in the prejudice to which they were subjected. During fieldwork, for example, two key informants who worked in a community-based health group began to mock and criticise a male trainee who had recently joined the organisation. They linked this individual's Mirpuri background to their opinion that he was 'male chauvinist, work shy, wouldn't talk or take orders from women'. His beard and *topi*⁴⁶, the fact that he wore trousers above his ankles and sandals without socks were also objects of laughter.

⁴⁶ see Glossary: Appendix 1

Many of these criticisms relate to religious forms of appearance and behaviour. Keeping a beard and keeping the ankles uncovered is a command for men in the *Sunnah*⁴⁷ and the fact that this individual would not speak to women freely could also be interpreted as modesty encouraged by religious teachings (Quran, 24:30)⁴⁸. When I suggested this alternative interpretation, however, the sincerity with which the trainee practised his faith was called into question – if he were a ‘practising Muslim’ he would not be away for two hours whenever he went to the mosque. The relationship between belief and action is explored later in this chapter; however this instance demonstrates that seemingly virtuous actions could be understood to have underhand motives. An assessment of intentions could thus make the difference between moral approval and condemnation. Furthermore, criteria other than those offered by scriptural authorities were called upon to interpret the situation. Interaction between men and women was presented as a necessity for work: ‘You’ve got to be able to work at a professional level, have a professional relationship.’

The negative views about religious dress and the linking of these views with Mirpuri origin demonstrate some complex thought processes at work within the Pakistani community. Mirpuri Pakistanis were often criticised by Pakistani respondents, including some who were themselves from a Mirpuri background. Criticisms often related to attitudes linked with lower levels of formal education but also referred to living in the past or trying to continue life in the UK along exactly the same lines as in Pakistan. Attitudes to social change are examined more closely in the following section, however, it is worth noting here that Mirpuri families could be accused of living in the past both in relation to how they practised their faith and to their expectations of healthcare:

‘Some people, particularly our Mirpuri community, have a weakness that they are not satisfied without an injection or expensive medicine. They want a system like our own country, but there, doctors prescribe things you don't even need and sell expensive medicines, because they want to earn money. They have that situation in their minds.’

(NuB - male with coronary heart disease)

⁴⁷ eg Hadith 7/678 (Khan 1987)

⁴⁸ see Pickthall 2000

Failure to adapt to life in the UK was portrayed as the reason for their approach to healthcare services and for expectations that were considered inappropriate. These attitudes indicate that, some Pakistani people thought that religious and ethnic traditions acted as a barrier to adapting to the UK context. This was another area of debate within the community; views on the necessity and desirability of social change are explored further in the following sections.

8.4 Attitudes to social change

This section explores shared understandings within the Pakistani community on the issue of social change. This issue is of relevance because of the relationship that has been shown to exist between social change and widening health inequalities (Scambler 2002). In relation to adapting to the UK context, a distinction was sometimes drawn between aspects of tradition that were and were not influenced by Islam, although, as highlighted above other frameworks could also be used. The numerous influences on culture within the Pakistani community were often recognised as being equated with religious influences, as though Pakistani and Islamic culture were identical. The Pakistani community (with particular reference to the Mirpuri community within this) was often criticised for not differentiating enough between ethnic and religious aspects of culture (see Chapter 1 for the distinction drawn in this thesis between these two aspects). In practice, this meant that ways of life that should be open to change were treated as though they were fundamental principles that should not be compromised. This position was seen by some Pakistani respondents as being against the spirit of Islam:

‘What [Islam] has always done, it’s allowed cultures to flourish so long as they’re in tandem with the underlying ethos of the principles of Islam, which is something that our community here fails to recognise. Quite often what we find is that when people become Muslim, quite often people are telling them to go and wear a *shalwar qamiż*⁴⁹... or learn Urdu and say, for example, in my local Mosque a number of local Afro Caribbean people who have become Muslim, and because of the fact that everything still runs in Urdu or Mirpuri or whatever languages, they’ll come in and mockingly start speaking Urdu because that’s the only way they can be heard. So I think that what we have done is confused the issue to a large extent and really, on the whole we have no problems with the vast majority of culture, or we shouldn’t have, as long as it doesn’t undermine what we stand for and what we believe in.

(Key Informant, Pakistani GP and academic)

As the above extract highlights, many Pakistani Muslims accepted that social change within defined boundaries was inevitable and necessary to the acceptance and practice of Islam in a new environment. However, the position of these boundaries could be a matter of debate and arguments based on Islamic teachings could be used to support different points of view.

Social change could, as above, be seen as necessary and unavoidable by some if the community was to successfully become part of UK society. Paying insufficient attention to religious values and blindly following the example of those who were not Muslims could, however, be seen to threaten traditional values and the lifestyles which sustained these. Diverse perspectives often resulted in conflict and accusations of unIslamic behaviour. Those who resisted taking the lead from examples outside the Muslim community were accused of being ‘cave Muslims’ on one e-list⁵⁰, that is, taking a primitive approach to Islam. Counter accusations pointed to the adoption of non-Muslim role models and practices and the use of value frameworks other than the Qur’an and *Sunnah*⁵¹.

However, those who defended longstanding values and practices did not always consider change as negative. The most important criterion for many in this camp was whether

⁴⁹ see Glossary: Appendix 1

⁵⁰ see Data Sources pp 67-68

change conflicted with the principles and teachings of Islam. People in all respondent groups recognised and accepted some changes to traditional Pakistani culture that were a result of living in the UK. Many Pakistani people, for example, especially those brought up in the UK, did not eat a diet based solely on traditional foods but ate a wide variety of dishes taken from a range of ethnic diets. Objections to such dietary change mostly centred on health concerns such as whether non-traditional foods were fresh or easy to digest, rather than on the loss of tradition.

However, if clear religious boundaries were threatened, for example, when meat suppliers mixed pork with chicken products, unknown to their customers, then Muslims across the country were 'horrified' and the issue was taken up at a national level (Buaras 2003). Here the distinction between *halaal* and *haram*⁵¹ food and the fact that people buying food in good faith were eating something forbidden by religious teachings caused great offence. These findings suggest that on some issues the Pakistani community is more amenable to social change than on others.

On some religious principles, however, there could be less unity. For example, fieldwork showed that the degree of flexibility on gender separation and dress requirements was a matter of debate within the community. Those who promoted change in these areas often drew on arguments that were not based on teachings within Islamic scriptures (as in the views of 'professional' behaviour highlighted earlier in this chapter). The use of these other frameworks was not always recognised, however, as many people within the Pakistani community lacked the ability to make a distinction between Islamic, as opposed to other influences on Pakistani culture. There was evidence during fieldwork that respondents within the Pakistani community could define as 'Islam' principles for which there was no scriptural authority. Mr L, for example gave a definition of Islam which does not tie in very well with the way it is described in the Qur'an and *Sunnah*:

'In Islam there are three things, three principles. First you shouldn't eat from your daughters' houses, secondly you should treat women well, third you should move things from the road to help other people.'

(NL)

⁵¹ see Glossary: Appendix 1

Although two of these principles are based on Islamic teachings, not eating from the house of a daughter is a principle in Pakistani culture that does not originate from Islamic scriptures. Furthermore, Mr L's 'three principles' do not accord with the foundations or 'pillars' of Islam as described in the following hadith⁵²:

'Islam is that you worship Allah and do not associate anything with Him and you perform the prescribed prayer and you pay the obligatory poor-due (Zakah) and you observe the fast of Ramadan.'

(Hadith 3: Ali 1990)

This confusion between different influences on Pakistani culture was addressed by people within the community in different ways. Some accepted longstanding traditions as ones that should be maintained despite the absence of scriptural authority. Their reasons for doing so were simply that there was no harm in such interpretations and that they resulted in good actions. Those who opposed defining Islam according to non-scriptural sources, however, pointed to the confusion that could and did arise as a result. This confusion exists both within and outside the Muslim community and is apparent in descriptions of Islam and Muslims written for health and social care practitioners. Many textbooks present the culture of a particular Muslim community, with all its different influences, as Islam. Thus statements such as 'women and children under seven generally do not attend the mosque unless for special occasions' are presented in well-intentioned textbooks as being the teachings of Islam (Fisher 2001 p4.48) but may only be true of one community or group, or even of a particular geographical area, and are negated by scriptural evidence (see also Henley 1982 for early examples of this approach). Such generalisations, taken from the practice, rather than the principles, of Islam fail to represent this religion on the basis of either its sources of authority or of its diverse interpretations.

Fieldwork revealed that both health professionals and Pakistani people could feel confused by conflicting practices which were all described as 'Islamic'. The boundaries of what does and does not constitute Islam were felt to be impossible to define by some Pakistani people if the practice of Muslim communities is used as a yardstick. Some members of the Pakistani community adopted the view that Islamic scriptures should define Islam and that reliance on the original sources of authority for this faith was the most valid position. This

⁵² see Glossary: Appendix 1

position accords with that taken by scriptural authorities themselves, which offer clear guidance about incorporating other sources of influence into the practice of religion:

‘Follow what has been sent down to you from your Lord’ (The Qur’an 7:3)⁵³

‘Whoever adds something new in our matter (Islam), it will not be accepted’

(Hadith 5: Ali 1990)

Religious teachings about health and related issues offer a useful starting point for interventions that aim to address existing health beliefs within patient groups, as recommended by the BMA (British Medical Association 1995). It is useful for health professionals to know, for example, that sugary drinks or traditional foods that are high in fat are not protected by religious boundaries, which focus more on whether food is *halaal* or *haram*⁵⁴. Evidence from this study indicates that people with chronic illness usually made an effort to cut down on high fat foods and sugar in accordance with professional advice, however, if they resisted change, professionals felt unsure about how far they could push. It is likely that the professional blurring of ethnicity and religious identity decreased confidence to persuade Pakistani patients for fear of causing offence. This suggests that increased knowledge about the boundaries set by religious teachings in relevant areas, and about the flexibilities that may exist within these, would offer health professionals a clearer understanding of possible areas that could be negotiated with Pakistani people with chronic illness.

Additionally, religious teachings may, as will be highlighted later, help to reinforce health promotion messages to avoid harmful foods and substances. They may also contribute to understanding how the wider determinants of health, such as community cohesion and social networks, are expected to operate in the Pakistani community. For example, as already mentioned, social visits to those suffering from illness are encouraged in Islamic teachings. These teachings also lay down a duty of care towards family members as well as others in need, particularly parents. Expectations of family members could, however, be significantly affected by work patterns in the UK, which meant that this duty of care could not always be fulfilled:

⁵³ see Pickthall 2000

⁵⁴ see Glossary: Appendix 1

‘Whether I am happy or unhappy with the family it does not make any difference... the family is busy with their own affairs. They ask if I need any thing, I am well what more. They do as much as they can, they cannot do more, after all they have to feed their own children. Its not like India, everyone is busy. You might be thinking about your mother, wherever you are you will be thinking how she is, but you would still have to work.’

(NJ - male patient with chronic skin condition/paralysis)

This suggests that initiatives to increase levels of employment in this community, which are currently significantly lower than the general population, will need to take account of the fact that levels of caring are significantly higher than in the general population (Office for National Statistics 2004). Improved employment levels may reduce support for people with chronic illness in this community unless strategies to help carers continue this support accompany schemes to improve employment opportunities. The balance between social capital and material capital will need to be carefully considered.

If healthcare professionals and policymakers are unable to differentiate between different aspects of culture within Pakistani communities, it is likely that either all aspects of culture will be treated as non-negotiable or else social policy will risk alienating those for whom religious teachings are an important consideration in social change. Although different interpretations of scripture may still need to be negotiated, findings suggest that knowledge of the underlying principles of Islam will increase the confidence of practitioners to negotiate treatment with Pakistani people with chronic illness. It is likely that this knowledge will also be helpful to the development of healthcare policy in relation to Pakistani communities.

The findings outlined in this section have highlighted the diversity of the Pakistani Muslim community, in terms of geographical origin and religious practice. Attitudes to social change are similarly diverse and reflect non-religious as well as religious influences and different interpretations of Islam. These influences combine to prevent wholesale abandonment of traditional ways of living but, at the same time, they present opportunities to explore the flexibility and diversity that exists within Pakistani communities. This exploration is an important step in the process of developing common ground - or shared

understanding - between members of Pakistani communities and other groups that make up UK society.

In the following section a more specific focus on understandings of faith in relation to chronic illness is explored. This influence is considered not only as it affects people with chronic illness but also their families and the Pakistani community in the fieldwork area. Analysis of the data reveals important lessons about the relationship between religious beliefs and the management of chronic illness. These findings have policy implications which are explored in the next chapter.

8.5 Shared understandings of faith in the Pakistani community

As already highlighted in Chapters 6 and 7, for people with chronic illness, Islam could act as both a personal and social resource for coping with chronic illness. Its ability to provide meaning for the experience of illness and to provide a structured routine for daily life was important to many respondents. Some of the issues raised have already been touched on in previous chapters as important context for understanding the processes of communication and decision-making. However, this section explores in more depth the shared understandings of faith that were apparent from respondent interviews, and the ability of people with chronic illness to draw on their beliefs as a resource for the management of their condition. Similarities and differences between the shared understandings of people in different respondent groups are highlighted where relevant.

8.5.1 Faith and chronic illness

As mentioned in previous chapters, religious teachings directed individuals to respond to adverse life experiences, such as illness, pain and anxiety with patience. Respondents felt this helped to diminish the anger and frustration that their condition could cause. An effort to be patient was not the only response described by respondents as a means of coping with chronic illness. Diversions such as going out or watching television as well as strict adherence to professional advice were also mentioned as coping methods. However, an important distinction was that acting on religious beliefs simultaneously gave meaning to the experience of having a chronic condition. Striving to be patient transformed the experience of chronic illness into a test of faith. Furthermore, whereas a response such as changes to lifestyle and regular monitoring of blood sugar levels increased patients' feelings

of control over the condition, a religious response acknowledged the limitations of this control.

The relationship of an individual to God was understood by respondents who spoke of this as one in which they submitted to His will. This association offered them tranquillity and the ability to carry on with everyday life:

‘Just leave it up to Allah. What else can you do? ... you have to do that, otherwise there’s no life.’

(LI - male with diabetes)

Thus the emotional and spiritual strength which individuals found in a religious response to chronic illness was an additional and distinct resource that could not be offered by other methods used to cope with their condition.

Islamic practices also offered physical ways of helping with the long-term experience of a condition. Respondents referred to a number of ritual practices as relevant to chronic illness and, in the longer term, their general wellbeing. Depending on the particular creed which individuals accepted as valid, a range of religious practices were mentioned. Ritual prayer and supplications as well as attendance at religious gatherings increased emotional strength and consequently the ability to cope with a chronic condition. A number of individuals felt these practices helped them to be more patient with their situation, particularly when they experienced pain or anxiety. Reading the Qur’an also helped people feel less anxious and more composed.

Other rituals were not accepted by all Muslims in the sample and related to the particular school of thought (*aqeedah*)⁵⁵ which respondents followed. Some respondents mentioned the practice of blowing on water after recitation of the Qur’an and then drinking the water as a means of improving their health. Going to saints or the graves of saints in order to pray for good health and wearing amulets containing verses of the Qur’an were examples of practices accepted as valid and useful by some respondents and dismissed by others as practices in which they did not believe. Diverse interpretations of Islam were influenced

⁵⁵ see Glossary: Appendix 1

by the choice of religious scholars an individual might follow or by the dominant way of practising Islam within a family or religious sect.

Religious practices often provided a routine or focus for activity during the day. Respondents described how they managed their responsibilities in between performing the five daily prayers or how they recited the Qur'an at different times of the day or night. Routines and established habits were generally seen as healthy and made people feel 'in control' of their lives. Respondents who built their routines around religious practices felt this kept them busy and purposive, and some felt this removed the need for social groups set up at community or day centres. In contrast, respondents who felt the lack of a routine, religious or otherwise, complained of boredom and a sense that their time lacked purpose. This sense arose from the impact of the chronic condition, which had often prevented people from working or being as active as they used to be. It was particularly emphasised by those diagnosed with depression; however, the breakdown of daily routine caused by chronic illness exacerbated the feelings of people with a range of conditions about loss of control and loss of their role within the family:

A: it is ideal for a man to have responsibilities and spend certain time with his family so that he does not have too much spare time otherwise he will lose his own personality. [Because of the chronic illness] he does not take care of his responsibilities and lots of other things get affected. If a man does not have a particular role - a job or business to go to then he does not have a fixed time for sleep, waking up in the morning or eating food - standard routine and lifestyle eventually disappears.

Q: How important is routine? ...

A: It is very important in a man's life... With routine everything is under control.

(CT - male with pericarditis and depression)

Family support for religious activity seemed to be as important as for other aspects of self-care such as diet, medication, attending appointments and even sleeping. Many respondents were reminded by family members to take their medicines at particular times or to attend appointments and found this helpful. As highlighted elsewhere, where such support was not available within a family, this could affect management of the condition. A

similar dynamic appeared to operate in terms of family support for religious activity. Both ZI and QI reported that their routine for ritual prayers during the day had stopped after marriage. This difference in routine, following change from an environment in which prayers were regularly performed to a situation where this was not the case suggests that social support for religious practice may be essential to many individuals. Without such support, an individual's capacity for religious practice appeared to be undermined and the emotional and spiritual benefits of such practices were consequently diminished.

The extent of religious activity could also be affected by the condition itself. Although for many people with chronic illness, their condition did not usually interfere with normal routines in religious practice, others did report restrictions on their ability to perform these acts. The impact of some chronic conditions was particularly noticeable in relation to fasting (see Chapter 7). However, feeling unwell could also limit walking to the mosque, reading the Qur'an and performing ritual prayers. Medication too, could limit ability to go out to the mosque if side effects meant constant visits to the toilet. In order to negotiate these difficulties, patients sometimes adapted the timing of medication to fit in with fasting or prayer. NE, for example, had established a routine in which his medication, which made him go to the toilet, was timed to fit in with ablutions for prayer as he felt 'both things have to work together'.

In addition to the influence of family support and of the chronic condition itself on religious practice, lifestyle patterns could have an adverse effect on establishing daily habits. Some respondents linked lifestyles that placed too many restrictions on time to the cause of their health problems. Interruptions to routine or inability to follow a regular routine was considered stressful and not conducive to a healthy lifestyle:

‘I’ve changed my lifestyle as well as little bit you know, I was doing taxi's for a bit you know, because I had an office in Bradford, I sold that, and then you know I was looking for somewhere in Leeds ...but ‘til I got that like I thought I'll do something a bit you know, with taxi's it's a different way of life isn't it, day and night job and you know, you just change your routine don't you, sleeping and eating and that, maybe I don't know ...whether that's causing it.’

(RS - male with diabetes)

The relationship between religious practice and a healthy lifestyle, and the support needed to put faith into practice, is explored further in the following two sections.

8.5.2 Religious responsibilities

Many respondents felt their lifestyles did not incorporate ritual forms of worship sufficiently and felt guilty that they paid inadequate attention to this area of their lives. The reasons for irregularity in such worship pointed to pressures that undermined a central position for religion in daily life. Patterns of work and sole responsibility for childcare meant that respondents often felt unable to perform the five compulsory daily prayers or attend religious gatherings because of time pressures. However some respondents recognised that this involved making a choice between religious and non-religious activities and involved decisions about how these should be balanced in relation to each other. Thus limited time was not always accepted as a reason and ‘laziness’ or lifestyle choices could be seen as an obstacle to fulfilling the requirements for ritual worship:

‘No it’s not time This depends on the person ...[those who] work from 8 o’clock in the morning until 5 o’clock in the evening and only get a dinner break, can’t get anything else in the middle, they don’t give prayer time.

(SQ - female with coronary heart disease)

Although these choices are made at an individual level to some degree, findings suggest that obstacles to prioritising religious practice existed at a social as well as individual level for many respondents. An exclusive reliance on personal motivation was insufficient for them to maintain the ritual actions that expressed their beliefs. A routine that made time for ritual worship and social support to maintain this routine could thus be a prerequisite

for prioritising such choices. Mr N felt that such support provided an environment of expectation and accountability, the loss of which had led to a drastic decline in religious practice amongst Muslims in the UK. He gave the example of a time when he found himself in a Hindu community and was not fasting in Ramadan:

‘I did not have this fear left that people would wonder what kind of Muslim I am, I wouldn’t be seen as an example of other Muslims if I did wrong, I openly started eating there - nobody would know whether I am a real Muslim or what ... here [in the UK] people are in that same position whereby people will not know them from a Hindu, Sikh or Muslim.’

TuC also highlighted the significance of maintaining a social expectation of practice within faith communities. She was concerned not to undermine the practice and expectation of fasting within the family by making it obvious to her grandchildren that she did not keep the fasts because of ill health:

‘If elders don’t keep fasts then it doesn’t have a good effect on the children so sometimes I used to say to them not to ask me whether I am fasting or not.’

Thus ritual practices provided a visible social presence to religion which was important to its continuity at both a personal and social level. Fieldwork showed that this social aspect of the faith community had been further eroded by policies that deliberately discouraged social interaction involving religion. A range of funding bodies excluded faith-based activity from the programmes they would support even though, as shown earlier, there was significant overlap between religious and ethnic identity. This aspect of social policy is dealt with later in this chapter, however it is worth noting here that the policy was sustained even where faith activity was not specifically excluded from funding criteria, by unofficial discrimination in the decision-making process. Thus, professionals within the Pakistani community, including those who sat on funding panels themselves, advised each other not to include reference to religion in any applications, as this was likely to prejudice funding panel decisions adversely. Most applications for funding from members of the Pakistani community were consequently packaged in relation to ethnicity, which is not the primary identity for most people in this community (Modood et al 1997), but was perceived to be a more acceptable frame of reference.

Taken together, the above points appear to constitute a range of demotivations to the practice of Islam at a ritual and social level. This could perhaps explain why some respondents, whilst professing a strong belief in Islam, did not practice the ritual elements of the religion or attend religious gatherings with any regularity. Their faith remained intact but the actions that might express that faith were not afforded the same priority, even though this provoked guilt and regret in the individuals concerned and a sense that the influence of religion on their lives was incomplete. For many Pakistani respondents spirituality or 'perceptions of the transcendent' did not translate into religiosity, 'behaviours and institutions that arise around these perceptions' (Selway and Ashman 1998). Respondents did not consider spirituality to be an adequate alternative to religiosity and felt that these two aspects of belief in Islam were complementary⁵⁶. This finding suggests that policies that address the faith practice of Muslims through the framework of spirituality utilise concepts acceptable within the dominant culture rather than exploring those which are more relevant to Pakistani Muslims (see, for example, Department of Health/NHS Chaplaincy 2003).

Nevertheless, practising the ritual elements of religion remained something to which many Pakistani Muslims aspired. QI, for example, who articulated her belief in Islam very strongly, believed the ritual acts of worship were 'right' even though she didn't manage to perform them, and defined those who did perform them regularly as 'devout'. Data showed that the definition of a 'religious' person was, however, relative to an individual's own level of religious practice. In contrast to QI, HX, who prayed and read the Qur'an regularly, did not define a person she knew, who also prayed regularly and had some knowledge of Islam, as 'very religious'.

Despite the absence of ritual worship from the accounts of many respondents, an active role in implementing and learning about religious values was, implied by their definitions of what 'being religious' meant to them as individuals. LI understood this to mean:

'Keep yourself straight, don't do anything wrong and don't let anybody make you do anything wrong ... [it's] our duty to get more into it.'

⁵⁶ see Chapter 1 for discussion of the relationship between spirituality and religion in Islam

Inner qualities such as sincerity, compassion and the ability to interact with others in positive relationships were seen as being just as essential to faith as physical acts of worship such as prayer. Definitions of Islam and of Muslims within the Qur'an and *Sunnah* often emphasise these spiritual elements of faith also; however, the meaning of ritual worship is of great significance in its own right. The ritual elements of religion were closely bound by a number of respondents to the foundations of Islam and basic to any definition of the religion. Thus prayer five times a day, the paying of tax on wealth (*Zakah*), fasting in Ramadan and performing the pilgrimage to Makkah were seen as essential elements of being Muslim. NJ felt that the absence of action to match beliefs meant that religion had become a theoretical or symbolic issue for some Muslims rather than having a practical meaning in their lives. He gave the example (raised many times during the study) of those who did nothing about the plight of other Muslims who were clearly suffering hardship. This understanding of the duty of Muslims to support each other related to both global and personal situations; the expectation of practical action to alleviate hardship for others implied that failure to do so was a reflection of weakness in faith or hypocrisy.

As mentioned earlier, these negative qualities were often perceived to relate to materialism, which promoted moral weakness, leading to inconsistency in the practice of Islam:

'Why are we getting so bad? We drink alcohol, read *Namaaz*⁵⁷, and do Hajj. We are greedy. We make friendship with money.'

(NL - male with coronary heart disease and diabetes)

Disillusionment with Muslims was nevertheless clearly differentiated from belief in Islam itself and religious scriptures continued to be a source of spiritual and emotional support for those who felt the Muslim *ummah*⁵⁷ was in a state of serious moral decline.

Disparity between professed belief in Islamic teachings and the actions of Muslims was subject to a shared understanding about the relationship that should exist between these two things. A mismatch between stated beliefs and actions was understood by many Pakistani respondents to indicate insincerity. LI, for example, felt it was more important to

⁵⁷ See Glossary: Appendix 1

fulfil his responsibilities towards his family and not 'do anything bad' than to perform actions that might be more visible in terms of expressing his faith:

'It's no good just going with religious groups to spread Islam and then committing a sin or thinking about somebody [in a bad way]. It's not right.'

Assessments of the motives behind any action were thus often given far more weight than the actions themselves. Relationships both within and outside the Muslim community were subject to these assessments; they included relationships with health practitioners, carers and others in the wider community and society. These relationships provide the context in which much chronic illness treatment and care takes place and the impact of this understanding is therefore explored in more detail below.

8.5.3 Belief and action

The previous sections have highlighted understandings within the Pakistani community that informed the expectations they brought to their interactions. As highlighted, there was evidence of a shared understanding that actions should not be judged in isolation but assessed in the context of the beliefs that drove them. Although not directly attributed to religion, this understanding was often expressed in relation to interactions with other individuals, views on community organisations and assessments of global events. Thus, the actions of health practitioners, community workers, media professionals and politicians were interpreted in relation to assessments of their motives.

The relationship between beliefs and actions has a strong basis in religious sources of authority⁵⁸. Many books by religious scholars often begin with the following *hadith*⁵⁹:

'(The value of) an action depends on the intention behind it. A person will be rewarded only for what he intended (Hadith 1: Ali 1990).'

Within an Islamic framework, an action can thus be judged as valid or unacceptable depending on the intention behind it. Human ability to judge the intention is accepted in Islamic teachings as flawed and limited and these judgements can therefore only accurately

⁵⁸ As well as this hadith, a number of verses in the Qur'an point to differences between stated beliefs and actions in relation to hypocrisy (see for example 2:14 and 3:167)

be made by God (The Qur'an, 29:10)⁶⁰. However, the nature of actions was used by Pakistani respondents to assess the sincerity of claimed motives and an indication of true beliefs. Double standards towards people from different groups, for example, were understood to reveal insincerity, hidden aims and hypocrisy. Intentions were of particular significance where money and jobs were involved. Community workers complained of the scrutiny and suspicion to which they were subjected by members of their own community, even though they were trying to contribute through their work to the community's wellbeing.

These findings are relevant to healthcare because they indicate the expectations Pakistani people with chronic illness have of healthcare practitioners. For example, the real priority afforded to patient wellbeing by GPs and hospital doctors was called into question by people with chronic illness and their carers when financial motives for giving or withholding advice were suspected:

'TC said that her GP often told her, when she took her young children in, that they should keep paracetamol and medicines at home, for the children. TC felt that they were trying to save money, and her husband said that they were trying to save money for the government ... [he] also remarked on the fact that he had not even known that it was possible to get benefits for caring for someone. His father had been disabled for over 11 years after a car accident, and all he got was his pension and income support. He had only recently learnt from the television about the fact that it was possible to get a Carers Allowance.'

(Fieldwork notes)

A mismatch between actions and purported beliefs was, however, not only identified outside the Muslim community but could be used for self-blame and criticism of Muslims themselves. As already highlighted, a disparity between beliefs and actions provoked guilt in a number of respondents about their lack of religious practice. These individuals accepted that their practice of Islam in daily life deviated from the teachings of the Qur'an and *Sunnah*⁶¹, which indicate a far stronger bond between belief and the practice of religious

⁵⁹ See Glossary: Appendix 1

⁶⁰ see Pickthall 2000

⁶¹ see Glossary: Appendix 1

rituals than some respondents maintained. The physical acts of worship such as regular prayer, charity and fasting are presented in these texts as part of the basic elements of faith:

‘And they have been commanded no more than this: to worship Allah, offering Him sincere devotion, being true (in faith); to establish regular prayer; and to practise regular charity; and that is the religion right and straight
(The Qur’an 98:5)⁶²

‘Islam is that you worship Allah and do not associate anything with Him and you perform the prescribed prayer and you pay the obligatory poor-due (Zakah) and you observe the fast of Ramadan’
(Hadith 10: Ali M 1990)

Scriptural descriptions thus present ritual worship as a basic requirement of being Muslim and a physical manifestation of faith in God. The spiritual aspects of faith are connected to ritual worship within these texts and were also understood to be connected by a number of respondents: TuC, for example felt that a simple approach to practising religion was to ‘just follow the main things, read your ritual prayers and that will teach you to do good deeds’.

Given this context, an expression of belief in Islam that is not followed through with ritual worship would appear to implicate individuals in the charge of insincerity. This interpretation is supported by the feelings of guilt and self blame expressed by a number of respondents. Semi-structured interviews and community fieldwork revealed that these feelings were not limited to individuals. Some respondents understood the widespread divergence between beliefs and actions as a malaise that affected the whole community and led to affording others the status that only God should be given:

‘To read *namaaz* is to show your gratitude to Allah and to ask for mercy and show you believe in one God, but in spite of that we bend in front of the authority, governments, idols and so on.’
(NJ - male with chronic skin condition/paralysis)

The influence of religion on decision-making (see Chapter 7) was felt by some to be compromised by this ambivalent relationship between faith and action. The following extract indicates that insincerity could also exist where religious actions were not linked to heartfelt belief:

Q: [The influence of] religion, is this more than the doctor, less or equivalent?

A: More I think if you believe in it, but we don't believe in it [properly]

Q: What do you mean that you don't believe?

A: It's like we will be reading [prayers or the Qur'an] but our concentration is elsewhere

(HX, female with diabetes)

The overall effect of this perceived disparity between belief and action was felt to be negative, causing moral weakness that affected individuals at a personal level and whole communities and nations in their relationships with other social groups.

Thus, whilst Islam itself was considered a positive force at a personal and social level, its potential impact on individual and community wellbeing was undermined in practice by the absence both of internal will and external support to implement the teachings of Islam into daily life in a practical way. Faith acted as a practical and spiritual support in daily life and a means of understanding experience at a personal level. Yet, individuals needed support from others in order to make time for the worship that was a vital element of being Muslim.

Visible manifestations of Islam, such as purpose built mosques and community fundraising events, were a source of self-esteem for the community and these were financed and driven by Pakistani community members on an almost entirely voluntary basis without external support. However, the small number of active individuals who drove forward these initiatives often felt under pressure and disillusioned because of the poor support they received from other members of the community, most of whom had limited capacity for voluntary activity, and the apparent hostility to faith activities from policymaking or funding bodies, who would not resource faith-based initiatives. Limited levels of visible faith activity were generally understood to be unhealthy and a source of concern both at

⁶² see Pickthall (2000)

the personal level (in relation to ritual worship) and at the community level (in relation to faith-based self-organisation). These complex dynamics resulted in both positive and negative consequences of being Muslim in the UK and these are explored further in the section below.

8.5.4 Being Muslim in the UK

As highlighted in Chapter 6, insensitivity and hostility to Pakistani Muslims was pervasive and could potentially affect almost all areas of life in which they interacted with other social groups. Apart from healthcare settings, education, work, neighbourhood, social group contexts and public places were all sites in which Pakistani respondents said they had experienced racism and Islamophobia. As will be highlighted later in this chapter, even within their own homes respondents experienced this kind of hostility via the media. The overall picture which emerged from community-based observation and respondent narratives was of small scale successes in integration and community cohesion against a wider background of ethnic and religious prejudice between the variety of different communities in the fieldwork area. This picture echoes findings from research carried out in the Leeds Muslim population ten years ago (Geaves 1995).

Even within services specifically aimed at meeting the needs of South Asian service users, there was evidence that faith needs could be neglected or deliberately omitted in ways that limited access for Muslim service users. For example, during the month of Ramadan, IN did not go to the South Asian elderly day centre she had been attending almost every day for the past sixteen years, because no meal was available when it was time for her to break her fast and transport was not arranged to take her home earlier. The centre was run by a Sikh couple who may not have deliberately discriminated against IN but who had not accommodated this religious requirement in the way the Centre was run. There was evidence of deliberate exclusion too, however, as in a funding application by the Hindu manager of another elderly day centre to celebrate 'South Asian multicultural festivals'. The application covered Christmas, Holi and Diwali (respectively Christian, Hindu and Sikh festivals)⁶³ whilst omitting the Muslim festival of Eid, though a Pakistani elderly group, in which members were all Muslims, used the centre regularly.

⁶³ Diwali is listed as a Hindu, Jain and Sikh festival in the Shaps Calendar of Religious Festivals (see Bradford District Council 2005)

This group was subjected to even more apparent hostility by a local authority exercise tutor. When one member of the group asked for the radio to be turned off, as this conflicted with her religious practice⁶⁴, the tutor told the group in no uncertain terms they would have to accept exercise with music or have no exercise at all. Women in the group relied on transport provided at the end of the day; those who felt uncomfortable had no option but to remain in this environment for the duration of the session. These instances highlight the hostilities that may exist between different religious groups within UK society (see also Farnell et al 2003), as well as the diversity in religious practice within the Pakistani Muslim community.

Within mainstream services and organisations respondents described wide-ranging situations in which their needs had not been addressed, resulting in services, which if used, involved compromising their faith. In health services, same-gender staff might be unavailable for women 'no matter how modestly a person dresses or how much they keep themselves covered'. The cultural values passed on within schools were often felt to undermine the values parents taught their children and failed to respect their religious identity. At work, too, ability to practice one's faith might be restricted by employers who refused breaks for prayer.

Failure to acknowledge faith needs could thus arise from neglect or deliberate omission and the reaction of many respondents was often not to challenge this failure. In all these circumstances, access to appropriate services involved having to ask for or even demand sensitivity. QI, an extremely articulate woman who had often advocated on behalf of others, felt this was something she did not want to do. Although she preferred *halaal*⁶⁵ food in hospital she did not feel so strongly about it that she wanted to ask for it and she didn't want to be 'a nuisance to anybody'. Because insensitivity was so widespread, challenging it on every occasion could become a constant and upsetting effort, with consequences for mental and physical health.

As highlighted earlier, the imposition of values that conflicted with Islamic principles was resisted and feared by many people, both within our sample and in the wider community.

⁶⁴ There is scriptural authority in Islam for not listening to music (Al-Kanadi 1991)

⁶⁵ see Glossary: Appendix 1

Many respondents and key informants talked about the challenge posed by living in the UK, particularly in relation to the education system and the media, which often promoted personal and social values that were hostile to those of Islam. The common disregard for beliefs held by Muslims and the danger of 'losing' children to other value frameworks was very distressing to a number of people and posed a barrier to attempts to develop relationships with people outside the community. The dominance of white culture in interactions was as much a problem in relationships with neighbours as in healthcare. CT and his wife felt the problems with integration arose from the dominance of these cultural values. Like many others, they felt that until the values of Pakistani people were given equal status to those of the dominant culture, Pakistani people would continue to be perceived as 'inferior' and 'outsiders'.

CT's wife referred to the negative influence a white friend, who became like a family member, had on their son's attitudes towards parental authority, an important value in Pakistani culture:

Wife: In the long run he affected us as our son has 50% of him which thinks like white people... he was a child then aged about 11-12 years but children pick up things without noticing and after I noticed some of his thoughts I used to tell my husband, "He may be a nice person but to protect our daughter and other son from these thoughts we'll have to part from him".

CT: He [son] became very rebellious.

Wife: He said, 'Why can't I go out on a weekend when other children can?' He [friend] was saying 'If your father says you can't go tell him you're old enough and you're going'...It's not his fault. He's been brought up in a different way, their system is like this ... we're old now aged 50 years, even if our father whistles we have to go running. It's our duty, it's not in their duty, that's why people get stuck between the two cultures and we both decided to move away from him.'

Respondents found such dynamics in interactions with those outside the community stressful and consequently attempted to avoid situations in which they experienced this stress. Reasons for isolating oneself from such situations were very similar to those given by people with chronic illness for not talking about their condition with those who did not

understand the way it affected their lives. QI described almost identical dynamics in her avoidance of interactions that left her feeling misunderstood and under stress:

A: That's why I avoid everybody. I actually don't want to get involved. That's why I don't go where there's a lot of people who know me. It's not just the Asian people, it's even English people ... I don't want to go, because I get invited they ask me this and ask me that - and I just can't be bothered explaining to everybody... So I want to go somewhere where it's neutral...Then I'm just like everybody...I mean it's not a matter of pride, it's a matter of self-preservation, really...See, now I'm getting pains all over... These are nerve pains. They're not circulation pains.

Q: Right...is it because you're talking about these things?

A: I think I am, getting over-excited.

QI's narrative implies that being 'just like everybody' involves being understood and accepted as part of the community but with sensitivity to the impact of chronic illness on her life. Findings show that Pakistani people with chronic illness often experienced insensitivity to the impact of chronic illness within the Pakistani community and insensitivity to their faith identity outside the Muslim community. It was often difficult, therefore for them to feel fully accepted in either context and shared perspectives could not be assumed in most social settings. The extract above suggests that feelings of exclusion could result in physical symptoms of ill health.

The importance of being accepted as part of the mainstream was also raised by a key informant in relation to service development. Recruiting Pakistani staff into the workforce meant being sensitive to their needs but in ways which did not mark them out as 'other':

'Nobody wants to feel different, so if you suddenly start treating nurses in a different way then they, well, that's not my experience of how people want to be treated....'

(Chief Nursing Manager)

As highlighted earlier in this chapter, Pakistani respondents who advocated acceptance of social change saw this as necessary to the acceptance of Islam in the UK. The position

they adopted involved negotiating a middle road between abandoning Islamic principles and resisting any change in the traditions of the Pakistani community. From this perspective, change was seen as necessary and welcome so long as it respected and did not threaten the boundaries of Islamic values and beliefs. Respondents recognised that the Pakistani community was subject to power relationships in the area of social change. They were also subject to attempts to impose values and practices upon them and respect for religious boundaries could not be certain. Within healthcare, the balance of power was such that practitioners were not obliged to take account of the religious boundaries within which Pakistani people acted and could impose their own values on patients.

‘I think the biggest barrier is the culture, this is not only for those who don’t know the English language and laws but also for those who are familiar with them... The way the health service treated my wife and I, we felt there was a cultural problem which is not from our side but from their side. They think that we are outsiders.... Whether they know the culture or not, they are not interested. They are only interested in what they want to do.’

(CT - male with male with pericarditis and depression)

Interaction could thus lead to adverse consequences at a personal and social level. For Pakistani Muslims generally, negative coverage in the media (see below) added to the constant awareness of discrimination. Withdrawing from such interactions was a means of protecting oneself from these consequences, yet in the public domain this was presented as isolationism and failure to integrate into UK society⁶⁶. Thus it seems that in relationships with other communities, Muslims in the UK who wish to keep their beliefs intact are in a bleak position, restricted and frustrated in their attempts to interact and yet condemned for not initiating such interaction.

The previous two subsections have considered the way Islam and its teachings are incorporated and understood in the lives of Pakistani individuals. In the next subsection the way these understandings of Islam were used by community-based health and social care agencies are analysed. Data from the study is explored in relation to how health and

⁶⁶ These criticisms were made by backbenchers within the Labour party and publicly supported by David Blunkett, Minister for Education at the time (BBC 2002; Younge 2002).

social care was adapted for delivery to Pakistani people and other Muslims in the fieldwork area and how faith affected relationships in this context.

8.5.5 Using shared understandings in health and social care

As highlighted in Chapters 6 and 7, practitioners and people with chronic illness rarely discussed faith beliefs and where they did, this was initiated by patients in order to address a practical issue such as how to adapt medication to fasting. Although there appeared to be almost no attention to religious beliefs in mainstream healthcare, community organisations run by Muslim staff did sometimes make use of faith as a resource in health activities. As highlighted in Chapter 7, using religious teachings with health messages was an important means of adapting health promotion messages to the cognitive framework of those who attended these activities and increasing trust in the workers. At the same time, it was important for workers to be seen as 'genuine people' in order to be accepted.

This authenticity was considered essential and is reminiscent of earlier findings about the relationship between intentions and actions. Dishonesty could discredit actions which, on the surface, might be worthy. This understanding was one that Pakistani respondents appeared to apply to interactions in general. Staff in community-based organisations did not believe an Islamicised health promotion message would be as accepted from a non-Muslim and felt that women in the group might perceive this as manipulative. Although this view was not based on empirical evidence, they felt that believing in certain values was a prerequisite to using them as a resource.

These views require further evidence to support them, however, they suggest that the values on which healthcare services are based need to be accepted by practitioners, patients and carers alike. They also support the argument that mainstream service development to address diversity in health and social care should focus on cross-cultural frameworks that are as inclusive as possible if they are to be accepted as valid by all stakeholders (Mir et al 2001).

For example, as already mentioned, showing concern for those who are ill by visiting and offering support is encouraged through Islamic teachings, as are duties of care towards family members, relatives and neighbours. These values have cross-cultural resonance (Walsh 1998) but were rarely promoted by health professionals during fieldwork interviews

or observation. At times, they were undermined by practitioners who placed far more emphasis on 'self-care' and 'independence'. Independence and the ability to look after oneself were also valued by Pakistani people with chronic illness also, but not exclusively. Incorporating all the above values in healthcare advice would allow the emphasis on particular ideas to be drawn by patients and their families, rather than decided beforehand by practitioners.

Analysis of data from the research also shows, however, that shared values were not the only consideration for health promotion. The status of the person giving the health message and his or her ability to relate to the everyday reality of the audience was also considered crucial. Findings presented in Chapter 7 reveal that information tailored to the personal needs of people with chronic illness appeared to have most influence on decision-making about health. Fieldwork showed that ethnic background could also affect the level of influence or input professionals were able to have in a particular community.

The 'Healthy Living' group had originally set out to include the two major communities of Muslim women in the area, however, cultural factors other than religion were a further issue discovered to be of significance by the organisation. Bangladeshi women did not attend the exercise classes run by the organisation because workers did not speak Sylheti and were seen as 'Pakistani' (even though one of them was Indian). The influence of ethnicity was also apparent in dietary differences between Pakistani and other Muslim communities. The diet of Bangladeshi Muslim or Arab Muslim families, for example, is made up of very different ingredients and different ways of cooking than that of Pakistani families and this diversity is even greater if regional differences are also taken into account. Staff running projects that gave advice about 'healthy eating' recognised the need to consider such variety. Nevertheless, even where a common faith existed, ethnic differences could form a barrier to group participation, despite organisers' attempts to make individuals feel welcome.

Barriers relating to ethnicity appeared to be far stronger where language differences hampered communication. Some community groups for South Asian people were attended by Indian and Pakistani individuals of different faiths who shared a common language and interacted in social and educational activities with some separate faith-based activities. However, even within these groups the religious and ethnic background of staff

could significantly affect membership and opportunities to participate (as with the day centre manager mentioned earlier). In practice, where key staff did not reflect diversity themselves, groups for 'South Asian' people were usually dominated or attended solely by people from a single religious and ethnic background.

These findings suggest that a common language, a focus on areas of common ground and accommodation of separate faith-based activities can form the basis of successful interaction between people of different ethnic and religious backgrounds. Power relationships will also need to be addressed in such groups so that decision-making processes allow equal authority to individuals from the diverse groups represented.

Shared beliefs, the ability to communicate effectively and shared power, appeared to be prerequisites to the successful organisation of multicultural groups. In groups where English was most commonly used (usually involving professional or younger people educated in the UK) shared beliefs emerged as a primary force for participation. Ethnic differences became a secondary issue and group members felt a common faith or common goal was the strongest bond between them and often a crucial reason for participation.

Findings in this section have demonstrated ethnic variations in the incorporation of Islam into lived experience. They have also highlighted how faith and other aspects of identity affect interactions between different social groups. Despite its historical origins in the Arabian Peninsula, the religion of Islam has successfully been incorporated into a variety of cultures worldwide. The need to create a niche within British culture was recognised by individuals from the Pakistani community in relation to how Islam should be practised in the UK. However, the terms on which this niche should be created, and the degree of flexibility that Muslims should adopt in relation to Islamic principles, are areas in which debate continues within the community itself. The following section looks at interactions between Muslims and the wider society in terms of common ground and difference. An understanding of both these areas is important to finding inclusive frameworks for social policy that can be comfortably accepted by Muslims as well as others in UK society.

8.6 Interactions in the wider society

Previous chapters have demonstrated that religious beliefs affected the decision-making of Pakistani people about chronic illness management and their understandings of the

meaning of illness in their lives. These chapters have also shown that, despite this, people with chronic illness sometimes expected health professionals to consider these beliefs and religious acts such as fasting to be unimportant and that they consequently did not consult their doctors about such aspects of their experience. As highlighted earlier, Pakistani respondents anticipated that professionals were not equipped to give advice in relation to religious obligations, and that, if given, their advice could be subjective rather than impartial and inclined towards undermining rather than supporting their faith. In practice, professionals could be more sympathetic and sensitive to the significance of religious practices than expected. At the same time, findings show that most practitioners were guilty of poor cultural competence in this area and needed training to deal with religious influences on health sensitively.

Further evidence from the study helps to explain why Pakistani people with chronic illness held these low expectations of professionals. The lack of opportunity to engage in discussion of the beliefs of Muslims in a climate of mutual respect was reflected in the wider social setting. The media, in particular, reinforced the notion of a vast cultural divide that could not, indeed should not, be bridged. At the same time, though rarely, media channels could be used in ways that promoted the wellbeing of Pakistani people. The impact of the media on respondents' wellbeing, both through its influence at a personal level and at the level of social policy, are therefore considered below.

8.6.1 Media impact on wellbeing

As mentioned previously, fieldwork showed that Pakistani Muslims felt the influence of the media, especially television, to be generally hostile to the wellbeing of Muslims in the UK. The values in which media messages were embedded had a significant influence on their acceptability to people living in the Pakistani community. Those that reinforced respondents' own beliefs were felt to contribute to wellbeing, particularly when they were expressed from a source perceived to be trustworthy and authoritative in this respect:

‘On Asia Net, when you know, this, *Maulana jee* [religious teacher] when he comes on and he speaks, especially when he speaks in English, and I’m listening and I find that wonderful...I find it relaxes me if I’m feeling tense, or something like that. In fact, I did record one or two programmes like that, so I listen to them.’

(QI, female with hypertension, diabetes arthritis and coronary heart disease)

Religious leaders or teachers could thus improve wellbeing, without being involved directly in healthcare. The perspectives that religious teachers could offer, made accessible to many people via the media, contributed to psychological wellbeing even though, as highlighted earlier, many respondents felt that *imams* and mosques were not appropriate people or places to go for reliable information and advice about health. These respondents associated authoritative treatment for chronic illness with healthcare professionals and findings suggest that, at present, people with chronic illness do not consider the two types of support to be associated.

The kind of media programme described in the above quotation was rare on mainstream channels and there was a consensus within the Pakistani community that the mainstream media played a significant part in creating and maintaining Islamophobia in the UK. Patients and individuals within the wider community sometimes referred to mistrust of some media sources, which were believed to spread political propaganda rather than provide an objective or balanced view of events involving Muslims. The media was thus perceived as attacking and damaging Islam and Muslims, as most often denying Muslims a voice and as presenting them and Islam in an unfavourable light.

Some attempts to redress this balance were noted by subscribers to internet e-lists, who urged others to acknowledge and encourage broadcasts which gave more positive coverage. However, favourable presentations of Islam and of Muslim perspectives could themselves spark virulent hostility – not only by counter articles and programmes denigrating Islam and stereotyping Muslims⁶⁷ but also through internet viruses targeting activists, e-list subscribers and websites. This kind of opposition was particularly marked in relation to

⁶⁷ For example Julie Birchill’s column in *The Guardian Weekend* (18.8.01), in response to BBC’s ‘Islam Week’ (a result of two years’ lobbying by Muslims involved in the media) referred to the history of Islam as moving forward into ‘oppressive darkness’ and the veil as a ‘hideous mobile prison’.

activities that targeted Zionism or made accusations against the state of Israel⁶⁸. One UK e-list, which had itself been targeted, gave an overview of hostile opposition, which was described as operating at a global level:

‘.. activists report that people and organizations on their private e-mail lists: family members, friends, acquaintances, media contacts, government officials, interfaith relations organizations, activists, and activist organizations suddenly found themselves receiving tens, hundreds, or thousands of anti-Arab, anti-Muslim and anti-Palestinian "spam" e-mails per day. Many on private e-mail lists reported receiving anti-Arafat cartoons and racist diatribes, along with e-mails that aggressively connected to a web site that took control of their computers, turned the screen white, and made it necessary to shut down and re-start the computer. Some also reported that their e-mail addresses had been "spoofed" and their on-line identities appropriated for the distribution of racist messages.’

(Muslim Public Affairs Committee e-list)

The internet was a significant feature of media activity involving Muslims in the wider community. Attempts to threaten the status quo of current political and economic power relations with others in UK society could, similarly, trigger unwanted action by powerful opponents. For example, a popular website that called for a boycott of international companies supporting Zionism was forced to close down and reopen on another site because of the pressure placed on its server by the multinational companies involved.

The overall impact of the media on Pakistani Muslims was thus often perceived as generally negative and frustrating, with slight relief in the form of rare broadcasts that offered positive representation. Even though much of the hostility outlined above focused on non-Pakistani Muslims, the bond of faith between Muslims of different ethnic backgrounds was always given prime importance in respondents’ accounts of how they were affected emotionally by this kind of coverage. Thus, the position of Muslim populations in different

⁶⁸ A Channel 4 programme attempting to discredit members of the Muslim Council of Britain ('Who Speaks for the Muslims' 10th May 2002), and produced by an active Zionist, sparked a campaign of complaints by Muslims across the UK.

parts of the world was often the subject of discussion, and connections were shaped by a common faith, rather than ethnic identity.

The presence of the media was constant - all households in our sample at least watched television regularly, especially at times of global conflict involving Muslim populations. Hostile coverage was not limited to news however; fictional programmes involving Muslim characters could also promote Islamophobic ideas about Muslims as terrorists and as a threat to the safety of communities in the UK⁶⁹. Those who became involved in challenging media representations felt this was a site of constant struggle, not only to win over public opinion, but to achieve even a minimal voice for Muslim perspectives.

Most people in the fieldwork area did not engage in this struggle for various reasons: many lacked the skill or felt it was hopeless, others feared the personal consequences of being identified as an activist. Those who did engage with the media, however, saw this struggle as part of their duty to oppose oppression and to defend the community of Muslims against attack, a perception that has foundations in the scriptural sources of Islam (The Qur'an 2:193; 8:73)⁷⁰. Their attempts to influence public opinion and gain a voice for Muslim views were aimed ultimately at influencing social policy, which was perceived as having strong links with the media. These links between the media and social policy towards Muslims are considered in the following subsection.

8.6.2 Media and social policy

Media channels were often used to promote a particular social policy stance towards Muslim communities and reinforce particular assumptions about them. The excerpt from a national newspaper below attempts to use the example of a highly unusual secondary school as a reason for restricting social policy support for faith-based institutions. Under the headline 'Keep God out of class' and subheading 'One would have thought that September 11 would see off religious schools for good. About time too', it reads:

'Bushra Nazir, its Muslim head teacher, has gone to extraordinary lengths to accommodate every religion, with separate school assemblies for each faith, a flexible uniform, religious

⁶⁹ The Muslim Council of Britain held the BBC responsible for an attack on a Muslim university student and Islamophobic graffiti on Birmingham's central mosque following its broadcasting of a fictional drama about suicide bombers being trained in a Birmingham mosque (see Versi 2003).

⁷⁰ see Pickthall 2000

diets and closing early for the month of Ramadan, while celebrating Diwali, Christmas and Guru Nanak's birthday. Above all she manages to allay parental fears, urging girls into higher education. Results have soared from 28% to 59% gaining five A-C grade GCSEs, with many now going to university. With great care an ordinary state school can educate girls well, with enough sensitivity to satisfy religious anxieties - better by far than segregating the faiths. There should now be a freeze on any new faith schools and a ban on any religious selection. (Toynbee 2001)

Value frameworks imposed upon Muslim communities have already been highlighted in previous chapters. Initiatives that came from within Muslim communities themselves often had to negotiate ways of organising that were imposed upon them by those in power. One example of this within the fieldwork area was provided by a Muslim Girls' School, which had struggled to survive since its inception in 1994 against a background of opposition from the local education authority. The school came under threat of closure and attempts were made to transfer students into three separate schools, two of which were mixed gender. Examples of how far groups were allowed to retain their religious and ethnic identity also existed in relation to health activity; the local authority exercise instructor mentioned previously not only refused to run her session for an elderly women's group without music⁷¹ but also threatened to leave unless people stopped talking to each other in Punjabi during the exercises.

Debates about the need for separate services are also taking place in health and social care in relation to services for minority ethnic communities (Mir et al 2001). As highlighted in the section about community organisations (see Chapter 7) their lack of impact on mainstream service development is a reason why arguments to use resources differently might be made (Mir and Din 2003). However, reasons for opposing specialist services for Muslim communities differ significantly from those relating to services for minority ethnic communities. The titles for the above excerpt expose the reasons for opposition - institutions that cater solely for Muslims are seen to threaten a secular system and are linked to terrorism.

⁷¹ Some Muslims consider listening to music forbidden by Islamic teachings. See Al-Kanadi (1991) for scriptural evidence that supports this position

The existence of a long tradition of state-funded faith schools in the UK, which are almost exclusively Christian and Jewish establishments, suggest that such fears are based, at least in part, on stereotypical ideas about Muslims and are the product of Islamophobia – an important reason why Muslims want separate institutions in the first place. The values and ideals of Islam are presented in the above extract as extreme and incompatible with the value framework of secular organisations. In contrast, opposition to specialist services for minority ethnic communities is usually based on arguments that they are used to absolve mainstream services of responsibility whilst being under funded and insecure themselves (Mir et al 2001).

The positive benefits of organisations run by and for Muslim communities have been mentioned earlier; examples of innovative approaches to service delivery using faith as a resource are also detailed elsewhere (Mir and Tovey 2003). However, there has been a general failure in UK social policy to recognise the benefits of faith organisation by Muslim groups; those outside Muslim communities almost never acknowledged these during fieldwork.

This prejudice was not all one-sided. Muslim respondents often talked about the value framework of mainstream schools or UK society in a similarly polarised way, and stereotypes about people outside the Muslim community were noted during fieldwork. At the same time there was ample evidence both through individual accounts and community-based coalitions⁷² that members of the Pakistani Muslim population shared many ideals with those from other social groups in the UK. However, whereas changes in media or social policy perspectives to accommodate Muslim views had to be negotiated with those in authority, value frameworks could be imposed on Muslim communities without any process of negotiation, as highlighted in the examples given previously.

The stress caused by constant reminders of difference and of powerlessness is of significance in a study which explores health inequalities in this community. Psychological wellbeing has been established as a determinant of health in the wider literature on health inequalities (Marmot et al 1998; Marmot and Siegrist 2004) and is discussed in more detail in Chapter 9. Both media representation and social policy contributed to this stress in

⁷² For example, the Leeds Interfaith Forum, the Leeds Coalition Against the War and the Leeds Initiative.

important ways. Findings suggest that hostile and imbalanced media representation of Muslims could have an adverse impact on the wellbeing of people in Pakistani and other Muslim communities. Respondents who stopped watching the news at times of global conflict involving Muslims, or who tuned into satellite channels which provided a perspective sympathetic to their own were, in effect, protecting themselves from such stress. During fieldwork, numerous accounts highlighted the depression and distress caused by news of the oppression of Muslim individuals and populations. Though upsetting, many individuals did not feel able to stop watching such reports because of their feelings of responsibility towards those involved:

‘When I read all this I was very upset and even cried. I had a very bad headache all day ... I am more interested in this kind of news because it is obviously an injustice to us. It’s not like it doesn’t affect me because it involves you – we are linked to each other.’

(TuC - female with diabetes)

The need to engage with the media and with social policymakers was promoted by a number of Pakistani professionals involved in community organisations. The skills and means to influence the media and social policy decisions were considered essential, if Islamophobic practices were to be challenged. A workshop to train people in these skills was run a number of times in Leeds for this reason. At a national level, the number and membership of e-groups grew massively over the fieldwork period from a handful of academic or missionary groups, to countless e-lists which drew a far more varied membership. These were often used to mobilise Muslims for political purposes or to increase awareness of the politics and economic considerations behind global events such as war and occupation.

The way in which Muslims themselves made use of the media appeared to increase and change focus over the fieldwork period. Before the terrorist attack in New York on September 2001, leaflets encouraging charitable donations or advertising talks about Islamic teachings were most often distributed within the fieldwork area, along with the more political Muslim News publication which was distributed free to mosques. These media channels were also used to promote positive activity within Muslim communities. For example, the Muslim News Awards for excellence involved a high profile programme,

involving VIPs from the media and politics, and was advertised using glossy publications and a range of internet and national organisations. It aimed to 'acknowledge achievement and promote excellence within the British Muslim community [and] ... to identify the role models of tomorrow' (Muslim News 2000). The newspaper had itself become properly established as a consequence of Muslim opinion in the UK mobilising after Salman Rushdie's publication of *Satanic Verses* (Rushdie 2004) which most saw as an attack on the foundations of their faith (Muslim News 2000). The Muslim Council of Britain and Muslim Association of Britain regularly used e-lists as well as leaflets to promote their work and send out positive messages about Muslims in the UK.

These activities became significantly more political after September 2001, in attempts to mobilise the community against American and British attacks on Afghanistan and Iraq. At the level of group activity, a new organisation was formed within the fieldwork area to provide a stronger voice for Muslims in Leeds by acting as an umbrella organisation. Membership of the group was drawn from different ethnic communities, including Arab, English and African Caribbean Muslims, though Pakistani Muslims initiated the groups and were in the majority. Leeds Muslim Forum adopted a strong political lobbying subgroup and organised a number of community events to raise awareness both within and outside the various Muslim communities. This group was run on a voluntary basis and suffered from the consequences of having no staff or premises to anchor the organisation.

Muslim groups and anti-war groups acted independently and as coalitions to make their voice heard in the media. This change in community behaviour during the fieldwork period was more significant in many ways than the attitude towards Muslims within the mainstream media. Media trends did not change but became more widespread and intense (Whitaker 2002). However, engagement with the media and its use as a political tool became an act carried out not only by well-informed members of the Pakistani community but by many others, who had never before been involved in such activity but felt strongly about political or media attitudes towards Muslims.

Those who advocated this kind of engagement often made the case for doing so against arguments that 'nothing would change' and that those who did take part would be targeted by the authorities. An existing sense of insecurity within the community and of being subjected to suspicion was intensified after September 11, 2001. Most Muslims in the

fieldwork area and on national representative organisations felt that accusations about the identity of the terrorists involved had been made with insufficient evidence and that this was because, as a social group, Muslims were already subjected to suspicion and prejudice. Objections to becoming involved in protest marches were based on similar reasons of fear of the consequences and despair of any real change in attitudes, as well as the argument that asking for support from the very politicians who were oppressing Muslims did not make sense.

It is worth noting that similar fears of the consequences of taking part in this study and similar cynicism about its value were expressed by a number of Pakistani respondents, when fieldwork first began in February 2001, before the September 11th attack (see Chapter 5). As reasons for taking part offered an opportunity to influence health policy and practice, these findings suggest that engagement in such areas is, for Pakistani Muslims, tinged with an acute awareness of the prejudice to which they are often subjected and the insecure social position they hold in the UK. This awareness became even more intense after September 2001 and members of the Leeds Muslim Forum at one stage discussed the need for 'contingency plans' in case the UK became 'another Bosnia' and Muslims were driven out of the country.

People without fluency in English were particularly conscious of their powerlessness against those in authority. During fieldwork, some related anecdotes of how bilingual professionals had taped conversations which were then used as evidence against those being interviewed, for example, to take children into care. These findings have particular relevance to the development of social policy initiatives through community involvement – fieldwork highlighted cynicism with consultation exercises, which had a history of raising expectations but making no attempts in strategic planning to meet the highlighted needs of minority communities.

Despite these points of view, significant activity within the fieldwork area to engage with political and media sites of struggle continued. Coaches were organised by two mosques – one with a predominantly Pakistani congregation - to anti-war protest marches in London and local demonstrations were held in the city centre on three occasions. Articles and letters were submitted to the local newspaper about events in Palestine and meetings with local politicians were organised by Muslim groups. Leeds Muslim Forum attempted

numerous times to engage with all local politicians together, despite clear lack of interest from some; a meeting with Forum members was cancelled three times and three of the eight politicians failed even to respond to invitations to meet separately. Those who did agree to meetings sometimes insisted that these should be only with a limited number of their own constituents and during surgery times. Thus, despite attempts to engage with the political process, these dynamics demonstrate that failure to engage with social policy debates was not necessarily through lack of effort or, as the Home Office Minister suggested in 2001, failure to speak English (BBC News 2002).

Political and media activity was supported and organised by Muslims from Pakistani and other communities in Leeds in coalition with anti-war and interfaith groups. Those who participated in protests did so because of the injustice they felt was being perpetrated by the powerful against the weak. This shared understanding united people of all social classes, ethnic backgrounds and creeds in a common aim. Serious concerns about the differences between groups within this coalition existed both within and outside the Muslim community but were overcome by many who recognised the need to unite in order to oppose injustice, particularly as counter-alliances were recognised as being formed to support 'the ferocious onslaught' (Muslim e-list)⁷³ against Muslims worldwide.

Although these activities were carried out by a minority within the Pakistani community, their effects were felt by many more people within the fieldwork area. They presented a challenge to those both within and outside the community who did not actively oppose the *status quo* and they signified a will to engage in sites of power despite the struggle this involved and the possible consequences of conflict with powerful institutions. As such, the reaction to global events during the course of the study demonstrated an increased confidence by some members of the community to organise themselves and challenge both hostility and inactivity. In effect, these individuals and groups demanded the sensitivity to Muslim perspectives that was rarely apparent in interactions with those outside the Muslim community and which, at an individual level, was so difficult to constantly negotiate.

⁷³ The message containing this description was endorsed by Abd al-Aziz ibn Baz, a leading Muslim scholar

8.7 Conclusion

Findings presented in this chapter suggest that Pakistani individuals need social support to successfully incorporate faith beliefs into their daily routines and to draw on faith as a resource. Social policy support for faith identity can indirectly help Pakistani people with chronic illness by increasing the emotional and spiritual resources available to help them manage their condition. This kind of support is currently lacking within the Pakistani community and is deliberately restricted by social policy.

Findings reveal diversity in the way faith is understood both within and outside the Pakistani Muslim community. In this respect they confirm the already well-established argument that representations of Islam as a fixed monolithic culture are mythical (Said 1995). However, findings do not support the idea that Islam is no more than a series of Muslim identities. Shared understandings about the values and boundaries promoted by this religion show that it possesses its own culture, which can be, and has been, adapted to innumerable regional and local traditions. Furthermore, defining Islam as equal to the culture of a Muslim community could be seen as an extension of the idea that religion is no more than a social construction and that understanding of Islam should be restricted to its human elements (see Chapter 1).

This chapter has also revealed significant potential for finding common ground between the Pakistani community and other social groups in the UK. For most Pakistani people in the fieldwork area, the desire to be understood and accepted as part of the wider community was balanced against the need to maintain Islamic boundaries and the need for sensitivity to the impact of faith on their everyday life. Findings demonstrate that the media's role in promoting 'closed', or hostile, rather than 'open', or receptive, views of Islam (Runnymede Trust 1997) is a barrier to such acceptance. There is evidence too that Islamophobic representations in the media and by politicians can radicalise Muslims and drive them to engage politically despite the insecure social position they perceive themselves to hold.

The evidence thus suggests that better levels of shared understanding are needed not only between health practitioners and Pakistani people with chronic illness but between members of the Pakistani community and others in UK society. Differences in ethnic and religious background are not necessarily a barrier to achieving this understanding. For

Pakistani respondents, ethnic and religious affiliations appear to be of less concern in their relations with others than the values held by individuals, which are evidenced by the way they interact. Sincerity and willingness to offer practical support to others in need are considered key foundations for successful interaction by people in the Pakistani community. For practitioners, knowledge of Islam that enables them to ask sensible questions and to negotiate treatment without causing offence would help achieve the kind of understanding that is required.

Examples of successful cross-cultural interaction provide evidence that common values can form a solid foundation for social cohesion as long as power relationships are simultaneously addressed. The current lack of power experienced by people from Pakistani communities in their social relations with others in UK society, and lack of opportunities to engage, will need to be addressed in strategies to improve social cohesion within neighbourhoods, communities and society as a whole.

Findings in this chapter bring together issues raised in the previous two. The implications of these findings for policy, practice, research and Pakistani communities themselves are drawn out in the Discussion in Chapter 9.

PART IV: DISCUSSION

Chapter 9: Implications of the Study

Evidence for this thesis confirms previous research findings that people within the Pakistani Muslim community experience unequal relationships with others in UK society (Sheridan 2002). This is partly an experience they share with other communities because of the discrimination generally faced by minority ethnic groups (Ahmad 2000; Hatton et al 1998). However, Muslim identity exposes individuals and groups to additional discrimination, which impacts on a wide range of areas related to health and adversely affects wellbeing.

The aim of this thesis was to explore the influence of religion as a distinct aspect of identity within this social group. For many health professionals and Pakistani people, the distinction between religious and ethnic identity is blurred or not recognised (see Chapter 1 for discussion of this distinction). However, this confusion arises for different reasons in each group. Within the Pakistani community both types of identity are often closely linked in daily life; religious practices and ethnic traditions both contribute to social norms within the Pakistani community and for those who lack direct knowledge of Islamic scriptures it may be difficult to differentiate which ethnic traditions are rooted in Islamic teachings and which are not. For health professionals the lack of distinction arises due to poor understanding of both Islam and of ethnic traditions. This poor understanding is currently reflected in social policy (see Chapter 3). This results not only in an inability to differentiate between the two aspects of identity, in both policy and practice, but also to accurately assess the impact of each on health and wellbeing.

This study demonstrates that some Muslims will attempt to make a clear differentiation between religion and ethnic traditions. Tracing religious beliefs and practices back to their scriptural origins is a tool in this endeavour and this approach has been adopted in this thesis to differentiate religious from other influences on communication and decision-making.

However, others within the Pakistani community will lack the scriptural knowledge or inclination for this. Furthermore, findings show that strong links exist between ethnicity

and religion in areas such as language, diet, dress, and, most importantly, in relation to the prejudice to which people may be subjected. This indicates that in some areas these aspects of identity must be simultaneously addressed, rather than considered separately. It does not mean, however, that each aspect of identity does not deserve independent consideration and this thesis demonstrates that faith identity has a distinct and significant influence on the lived experience of Pakistani people with chronic illness.

As a group affected by multiple disadvantages, the experience of Pakistani people with chronic illness can be seen as a measure of how effectively health inequalities are being addressed by current policy and practice. In this thesis, I have attempted to move beyond asking whether inequalities in the health and healthcare of Pakistani Muslims exist (there is already abundant evidence that they do) and to answer the question – why do they exist and how are they built into policy and practice? Answering these questions points the way forward to how they may be most effectively addressed.

Quantitative evidence of the link between religious identity and the discrimination experienced by Pakistani people is currently sparse and is needed to supplement qualitative research of the kind this study provides. Nevertheless, Census data highlighted in Chapter 4 indicates that such evidence is likely to exist. The findings presented here have implications for policy both in relation to healthcare and to the wider determinants of health. Recognising the significance of religious identity and acknowledging its importance to the health and wellbeing of Pakistani people is a prerequisite to policy development that addresses the issues raised in this thesis.

This chapter attempts to bring together in a coherent way multiple themes that have been developed from multifaceted sources of evidence to explain these inequalities. The unequal power relationships that many Pakistani people experience and the dichotomy in community and wider perceptions of Islam suggest important explanations for the higher levels of mortality and morbidity in Pakistani communities. The following sections explore these issues in relation to social policy, healthcare practice, research and the Pakistani Muslim community itself.

9.1 Implications for policy

9.1.1 *Addressing inequalities in healthcare*

The study provides evidence that people within the Pakistani community experience unequal relationships with other social groups in UK society and that this is reflected in their communications with healthcare professionals. Dynamics of interaction within healthcare settings reflect the dominance of a European perspective in which religious beliefs, particularly those relating to Islam, which is often perceived as an underdeveloped and oppressive belief framework, are considered irrelevant to medical treatment. Unequal relationships with practitioners mean that people with chronic illness take the lead from professionals, who treat religion as a private matter, about what to discuss. Unequal relationships within the wider UK society mean that Pakistani people expect to be misunderstood and stereotyped by professionals from other faith backgrounds. This expectation is often justified; in the general population across Europe there is evidence of poor understanding of Islam and a culture of hostility towards Muslims, which bridges 'both the political mainstream and street extremities' (Allen 2002). In healthcare settings this culture may be replicated, particularly if there is no training on how to deal with cultural diversity or any challenge to stereotypes.

Findings suggest that where the issue of religious identity arises, the policy vacuum on how to respond is filled in practice with the dominant cultural norms of those who run particular services, and this can vary from one setting to another. Thus, where ignorance of Islam or hostility towards it prevails, stereotypical ideas about religious identity may be employed as an explanation for poor self-management of chronic illness, painting religion as a 'problem'. Challenging such ideas may provide the opportunity to review stereotypes, however, findings indicate that such ideas are likely to be part of the internal culture of a healthcare setting and to remain unchallenged.

The exploration of racism in this thesis reveals that ethnic and religious prejudice is combined in the racism experienced by Pakistani people. Inability to speak English and Muslim identity both inform the prejudice and stereotypes to which Pakistani people are subject. This prejudice has historical roots in colonisation, where language and culture were used as tools to dominate colonised regions (Muhammadi and Ahsan 2002; Said 1995).

Findings reveal that pockets of racism may exist even after institutional policies have been generally adopted. The quality of policy implementation in relation to interpreting services, for example, does not appear to be monitored by those with authority over clinical settings so that the standard of service delivery to Pakistani people with chronic illness may vary from one setting to another. The evidence suggests that racist attitudes and practices are easier to maintain in the context of organisational constraints such as pressures on time and poor training to understand the needs of Pakistani people. Failure to address these issues in clinical settings can mean that even when resources are made available they may not be effectively used because awareness of these needs is so underdeveloped.

However, the examples of good practice highlighted in the findings indicate that racism is not inevitable in healthcare and much can be done to increase the sensitivity and awareness of staff. The blurring of ethnicity and religious identity in healthcare policies has influenced the degree of attention paid to religious, as opposed to racial discrimination. Nevertheless, there is evidence that in some parts of the NHS the needs of Muslim service users are being considered. A recent guidance document (Department of Health/NHS Chaplaincy 2003) highlights the importance of meeting the needs of a multicultural and spiritually diverse society. Codes of conduct and processes for service development aim to be inclusive of people with diverse religious identities and people who have limited English. The guidance recommends robust recording of an individual's religion and wishes about contact by the chaplaincy service.

Evidence from this study confirms that access to and quality of healthcare both need to be addressed by policy to make any real difference to health outcomes for people from disadvantaged communities (Betancourt et al 2002). Findings suggest that policy development in this area needs to focus on raising the awareness of practitioners about the general importance of cultural competence but also on more specific aspects of treatment in which sensitivity to cultural practices may be particularly relevant. Many of the cultural influences on decision-making about chronic illness management described in the findings are unknown to practitioners. Healthcare policies which urge cultural competence need therefore to emphasise not only the general importance of developing shared understanding but also the specific impact of faith practices, or of travelling abroad, on treatment and medication.

At a broader level, the findings support the relevance of current policy approaches (see Chapter 3). However, in practice, it is clear that healthcare interventions based on these policies appear to be having little impact on the lives of Pakistani people with chronic illnesses. For example, appropriate training programmes that provide practitioners and Pakistani patients with relevant skills to interact effectively with each other are not in place, though training for practitioners and patients is clearly promoted in health policy recommendations (Department of Health 2001a; Department of Health/HM Treasury 2002).

Findings reveal that Pakistani people with chronic illness often feel vulnerable and uninformed rather than empowered with the skills and information to access services and manage their health effectively. Continuing failure to appoint and make effective use of bilingual staff and to develop cultural competence in mainstream services has been a theme of the literature on ethnicity and health for decades, yet resources are not often tied into policies that support these appointments⁷⁴. As a result service development in this area remains piecemeal and the absence of staff that can fulfil this role still continues to hamper progress.

The NHS Plan does offer strategies to address the determinants of health at a number of different levels. Individual lifestyle factors, social and community influences, living and working conditions and socio-economic and environmental conditions are balanced against each other in strategies to address, for example, heart disease in the general population (these wider determinants of health are discussed further in the next section). However, failure to target particularly disadvantaged social groups within these strategies means that they are overlooked in implementation. There is evidence that government directives on implementation of the Plan have failed to provide leadership in meeting the needs of minority ethnic communities. These directives have also militated against the development of innovative service models that would meet the needs of groups most affected by health inequalities (Woods et al 2003). Further evidence demonstrates that Health Action Zones have often created short-term projects that have proved difficult to integrate within mainstream organizations (Lawson et al. 2002). Findings from this study suggest that this

⁷⁴ The recent proposals to improve mental health services for minority ethnic communities are a notable exception (Department of Health 2003). How these are implemented in practice has yet to be evaluated.

kind of integration is crucial if clinical and cultural competence are to be combined for the benefit of Pakistani communities.

The current unjust distribution of ill-health and premature mortality in these communities has adverse consequences that raise both moral and economic questions for healthcare policy. Adverse trends in health inequalities are likely to continue, with widening gaps between those with the best and worst health, unless interventions to improve health outcomes target resources at those in most need. A recently published Health Impact Assessment of four regeneration projects found that one had the potential to widen health inequalities between different social groups:

‘as the project was not specifically targeted at the most disadvantaged groups it was unlikely to reduce health inequalities. A locational profile of a sample of existing clients identified disproportionate use of the service by residents from non-deprived communities.’

(Hirschfield et al 2001)

Evidence suggests that prevention must also be a major strategy in healthcare that aims to be inclusive of minority groups (Novas and Sacasas 1989; Horn and Beal 2004). Findings from this thesis suggest that models which give GPs responsibility for prevention - as the most accessible and influential practitioners - are likely to be most effective in relation to Pakistani communities. This will inevitably involve improving access to GPs as well as the quality of healthcare that GPs can offer. These improvements may rely on training sufficient numbers of professionals and perhaps following the example of other countries, in which family physicians are paid bonuses for improving the health statistics of the population they serve rather than for curative measures⁷⁵.

As highlighted at the beginning of this section, the dynamics of healthcare in relation to Pakistani people with chronic illness reflect dynamics in the wider UK, and indeed European, society. It is, therefore, perhaps unrealistic to expect healthcare policy and practice to develop in a vacuum. Inequalities in healthcare are a reflection of inequalities in other areas that determine health status and strategies to address health inequalities must

⁷⁵ E-list communication on the Health Equity Network from Peter Boume Chair, Medical Education Cooperation with Cuba (www.MEDICC.org)

take all these determinants into account. The following subsection explores this idea in more detail and attempts to link the findings from this study with other research that takes a broader view of health inequalities.

9.1.2 Addressing inequalities in health

This thesis began by asking the question ‘Does faith identity influence chronic illness management in the Pakistani community and if so, how does this relate to inequalities in the health of people from this community?’ Findings suggest that the dynamics of interaction in healthcare settings in relation to faith beliefs do help to explain why Pakistani people are likely to suffer more complications in chronic conditions and to experience higher mortality rates than the general population (Acheson 1998; Department of Health/HM Treasury 2002). Evidence from this thesis shows that unwillingness to discuss Pakistani culture, on which faith beliefs have a significant influence, is combined with poor accommodation of language difficulties to restrict both access to healthcare and the quality of healthcare received by Pakistani people with chronic illness.

However, the findings suggest further explanations for inequalities in health in the Pakistani community. Grounding this thesis in the mainstream literature on health inequalities offers important direction on how these findings should be interpreted. Healthcare itself has been recognised as contributing little to reducing these inequalities, except in relation to prevention; nevertheless, it is often a primary mechanism for policy implementation in relation to health inequities (Exworthy et al 2003; Hofrichter 2004). In the case of Pakistani Muslims, both religious identity and limited ability in English adversely affect social position and social relations not just in healthcare settings but in a range of contexts. The evidence suggests that these aspects of identity expose Pakistani Muslims to discrimination in a range of areas that have been shown to affect health status, such as education, employment and ability to participate fully in society (Marmot et al 1998). This suggests that action to deal with inequity in healthcare for this community must run alongside strategies to improve health status involving all the determinants of health. Otherwise the higher incidence of chronic conditions in Pakistani communities will not be addressed and healthcare will continue to reflect the disadvantage experienced by Pakistani people in other contexts.

There is evidence that awareness of the discrimination they experience is as significant to the health of Pakistani people as the discrimination itself. Self-perceptions of social position and social relations are markers of psychological wellbeing, which has been identified as an important indicator of health status (ibid). Although stress factors have previously been identified as relevant to addressing health inequalities in minority ethnic communities, these have been related to socio-economic position and membership of 'deprived income communities' (Horn and Beal 2004). Findings from this study indicate that stress factors for Pakistani communities are likely to include Islamophobia, and that this may equally affect those from higher socio-economic groups. There is further evidence that this kind of discrimination may be more intense for those who choose the 'visual identifiers' of Muslim identity, such as the hijab⁷⁶ (Allen 2002).

Findings related to the experiences of being Muslim in the UK indicate that belief in Islam can act as a powerful personal resource for individual Muslims, providing security, meaning and hope to people with chronic illness. At the same time Muslim identity is generally perceived as a social liability in UK society, and there is evidence that Muslims are subjected to far greater discrimination than any other religious group (Allen 2002; Whitaker 2002; Commission on British Muslims and Islamophobia 2004). Faith identity thus plays a dual and conflicting role in wellbeing because of the opposing perceptions of Islam within and outside the Muslim community. Whilst acting as a powerful cognitive and emotional resource for individuals, at a social level, being Muslim in the UK exposes individuals and communities to fear and uncertainty, injustice and distress.

This dual experience may help to explain the greater inequalities in health that Pakistani communities suffer, along with other Muslim groups such as the Bangladeshi community and Indian Muslims (see Chapter 1). The impact of this additional kind of discrimination is not currently being addressed by health and social policy. Indeed some policies are accused of legitimising Islamophobia and the social disadvantage implied by being a Muslim in the UK. Legislation such as the Terrorism Act (HMSO 2000b), for example, has been described as criminalising Muslim communities (Al Rashid 2002). Referring to a report by the Runnymede Trust and Commission on British Muslims and Islamophobia in 1997, the Muslim Council of Britain, one of the UK's leading umbrella organisations for Muslim

⁷⁶ See Glossary: Appendix 1

groups, recently condemned the lack of government action to address Islamophobia in the UK:

‘We strongly feel that the government has done little to discharge its responsibilities under international law to protect its Muslim citizens and residents from discrimination, vilification, harassment, and deprivation. The legal framework required to articulate standards of behaviour and to bring about a cohesive society remains as inadequate as it was when the report was published by the Commission in 1997.’

(Commission on British Muslims and Islamophobia 2004)

An approach to health inequalities in the Pakistani community that addresses these wider issues would accord with the most recent policy recommendations from research on inequalities in health (Marmot 2004; Hofrichter 2004), and the framework adopted by the NHS Plan (Department of Health 2000). Determinants of physical and mental health such as socio-economic position and social cohesion are recognised in the NHS Plan as being related to better health outcomes. The Plan further recognises that economic and social policies have a role to play in influencing these determinants so that they are amenable to change. As highlighted in Chapter 3, however, whilst recognising that change needs to happen, policy initiatives do very little to address ethnic discrimination and almost nothing in relation to religious discrimination.

The disparity between acknowledging health inequalities in the Pakistani community and taking action to deal with them is an issue that must be addressed if health inequalities are to be tackled. Currently, policies rarely acknowledge the significance of faith identity: the word ‘religion’ is used once in the introduction to the NHS Plan. Small scale examples of inclusive policies, such as the NHS Chaplaincy guidelines described earlier, or small local projects funded by Health Action Zone money, exist alongside widespread resistance and failure to support Muslim identity through social policy (see Chapter 3). This dichotomy reflects the lived experience of Pakistani respondents in this study, who also experienced widespread discrimination alongside isolated examples of good practice.

Findings indicate that a further issue for social policy development is the empowerment of people from Pakistani and other Muslim communities. There is evidence that patterned

persistent inequities in health are due primarily to power imbalances (Hofrichter 2004). Findings from this study suggest that members of the Pakistani community are adversely affected by such imbalances, involving religious but also ethnic identity, in many areas of their lives. Islamophobia and the repression of Muslim identity is currently seen to be legitimised by the state, increasing the sense of discrimination and exclusion felt by many Pakistani Muslims in the UK, in the same way as statements by far-right groups such as the British National Party (Burns 2003). Published statements by Government Ministers and politicians fail to recognise, or else assert a right to, the imposition of English culture upon Pakistani Muslims in the UK. They imply that 'integration' is a one-way process that must be initiated by members of this community (Younge 2003) and the aim of this process appears to be invisibility or assimilation (Allen 2002). Findings from this study show that the visible social presence of Islam is related to the self-esteem of Muslim communities and that this supports the ability of individual Muslims to sustain faith activity at a personal level.

The impact of these policies and political statements should not be underestimated. They result in high levels of mistrust and anxiety, so that even proposed legislation to prevent incitement to religious hatred is seen as likely to target rather than protect Muslim communities (Islamic Human Rights Commission 2004). Historical evidence demonstrates that much of this mistrust is justified (Al Rashid 2002). Added to this, poor levels of understanding and low acceptance of Islam and Muslims in the general population contribute to discrimination and act as constant reminders of second class citizenship. Consequently, members of the Pakistani Muslim community are often deterred from social and political engagement (Allen 2002). Visible and positive support in these areas needs to be demonstrated to this community if it is to have the confidence to engage in UK society without fear of discrimination or cynicism about outcomes.

Marmot (2004) has demonstrated that an individual's 'subjective status' is a strong predictor of health. How much control an individual has and the extent of opportunities for full social engagement in society have been shown to be crucial to explain health inequalities. Although much of the literature that relates markers of psychological wellbeing to health outcomes is related to work environments (Marmot and Siegrist 2004), those markers identified as being significant may be considered relevant to other contexts. Chandola et al (2004) have shown that the marker of low control as an indicator of poor

health status may be relevant to domestic as well as workplace settings. This suggests that findings from this study, indicating that members of the Pakistani community experience low control in social contexts, are likely to be relevant to explaining the health status of people from this community.

This thesis suggests that faith identity is likely to play a significant part in the subjective status of Pakistani individuals. This aspect of identity is subject to poor understanding and deliberate discrimination in UK society and these dynamics significantly limit the opportunities for full social engagement by Pakistani Muslims. Education, material wellbeing and the nature of community organisation are all adversely affected by religious discrimination which prevents people from this community engaging fully and on equal terms with other social groups in the UK. Findings show that Pakistani Muslims are subject to this discrimination not only from the dominant ethnic and religious group but also from other minority groups. This may help to explain why they do not appear to benefit from the improvements in health that have taken place in some other minority groups (Social Exclusion Unit 2001; 2004a).

Interventions to reduce health inequalities have been recommended in the areas of early child development, material wellbeing, the nature of work and communities and the circumstances in which older people live (Marmot 2004). Further evidence relating to the impact of childhood deprivation on health in later life suggests that failure to develop interventions in these areas for the current generation of Pakistani communities will have ongoing repercussions in the next (Acheson 1998).

Supporting, rather than restricting faith-based activity within Pakistani communities would appear to be one way of addressing the problems outlined above. The goals of current social policy in relation to communities promote social cohesion and the use of faith organisations as a resource (Department of Health 2000; 2004). However, this study demonstrates that these goals are undermined in practice by the lack of financial support available for faith activity by Muslims. As a result, groups within the Pakistani community may find it difficult to organise themselves in terms of faith identity or to develop the potential of Islam as a community resource.

The absence of social policy support for this kind of activity further acts to undermine everyday religious practice within the Pakistani Muslim community. This in turn diminishes the potential for individuals to draw on their faith identity as a resource for chronic illness management. Without the backing of social policy, community groups are unable to secure resources to offer therapeutic faith-based environments. Individuals are currently most often left to their own devices to use faith in a therapeutic way, though a very small number may obtain support from under-resourced and insecure community-based groups.

This study demonstrates that the framework of ethnicity offers an incomplete explanation of health inequalities in the Pakistani community, however, research on ethnicity may be helpful in pointing the way forward for policy development. Attempts to understand ethnicity as an aspect of identity have revealed that the experience of discrimination and perceived discrimination, rather than ethnic identity itself, is the most relevant indicator of health inequality (Karlsen and Nazroo 2002). This suggests that, in terms of identifying areas for policy intervention the most relevant question to ask might be 'Which aspects of identity or culture are subject to discrimination in ways that adversely affect health?' This is an inclusive question that allows religious and ethnic identity to be considered alongside other variables such as age, gender and social class. A social group that experiences discrimination within multiple categories is likely to suffer greater health inequalities than a group that experiences some, but not as many, kinds of discrimination.

Existing evidence demonstrates that the socio-economic position of Pakistani people is significantly lower than that of other ethnic groups (Office for National Statistics 2004). This study confirms that limited ability to speak English also contributes to inequalities in healthcare (Nazroo 1997). It adds to existing evidence by suggesting that religious identity is a further area in which Pakistani people experience discrimination and that this adversely and additionally affects health outcomes. Findings confirm that Pakistani women are subject to multifaceted discrimination because of stereotyped ideas about Muslim women (Anwar 2003).

This approach to understanding health inequalities helps to avoid essentialising any one aspect of identity so that it becomes an explanation for all disadvantage. The evidence indicates, for example, that difficulties in communication involving culture and language

are related not only to religious or ethnic background but may be traced back to social class and to lay-professional differences in beliefs and values (see the section on ‘Shared understanding’ in Chapter 7). At the same time, particular forms of discrimination and multiple discrimination may be highlighted in relation to the Pakistani community to offer reasons why its members continue to experience some of the worst health outcomes amongst minority ethnic communities (see Chapter 4).

The wider literature on inequalities in health points to a combination of factors – social, environmental and individual - as likely to explain differentials in health (Marmot et al 1998). Six types of capital are identified by Scambler (2002) as relevant to health and longevity:

- biological capital, which may be affected by class relations even prior to birth. For example, low income families are more likely to produce babies of low birth weight, who have an increased risk of chronic disease in adulthood
- psychological capital, which affords a capacity to cope with adversity
- social capital, which has to do with social integration, networks and support
- cultural capital, which includes opportunities for education and attainment that have long-term ramifications for employment, income levels and therefore, health
- spatial capital, or ability to leave areas linked to high mortality rates
- material capital, which is related to all the other forms of capital and linked to class relations.

(Scambler 2002 pp104-5)

Although there is evidence to support the idea that people from Pakistani communities are disadvantaged in relation to many of these types of capital (Modood et al 1997;), findings from this study are of particular relevance to psychological and social capital. Psychological wellbeing is characterised by markers such as social support, perceived inequality and perceptions of constraints (Marmot et al 1998). These markers of health status would appear to encompass experiences of racism and social exclusion, which have independently been suggested as affecting psychological wellbeing (Karlsen and Nazroo 2002). In relation

to the Pakistani community, findings from this study indicate that religious identity and limited English are both particular focal points of discrimination and exclusion in a wide range of settings. This discrimination affects the experience of healthcare in ways outlined in Chapters 6 to 8, but perhaps even more significantly, it is likely to affect other determinants of health, such as psychological wellbeing and socio-economic position.

Social capital in Pakistani communities is also affected by this discrimination. Findings suggest that faith-based organisations are an important element of social organisation in Pakistani communities, which are deliberately being denied opportunities to develop. Much of the disadvantage experienced by Pakistani Muslims is a consequence of resisting norms which relegate religious identity to the private sphere (Modood 2001) and attempts to make their faith less visible (Allen 2002). Accepting and engaging with Muslim consciousness on equal terms is, however, an important step in overcoming the historical European tradition of either fearing or controlling Muslim communities (Said 1995; Allen 2002). Research has linked regular participation in religious activity with increased community participation and strengthened family relationships (Smith and Faris 2002; Smith and Kim 2003). Media stereotypes, however, portray mosques, which are the centres of religious activity in Muslim communities, as terrorist training organisations (Versi 2003). Challenging Islamophobia is likely to be a key means of increasing social capital in this community. Findings indicate that this type of discrimination affects relationships between Muslims and people from other social groups in a huge range of contexts. The wider literature suggests that both state-level and neighbourhood social capital are relevant to health inequalities. High levels of reciprocity, trust and civic participation are associated with lower neighbourhood death rates, independently of material deprivation in these settings (Kimberley et al 2003).

Leadership by local and national government to address Islamophobia appears relevant to increasing both psychological and social capital in Pakistani communities. This thesis demonstrates that current policies reflect the dominance of white cultural norms, resulting in practices that are a constant reminder and source of stress, for those who do not share them, of their 'otherness' and separation from the mainstream of UK society. The evidence suggests a need to develop inclusive policy frameworks to address health inequalities and target policy implementation at those in most need. The need for inclusive frameworks is further indicated by shared experiences of discrimination across different

social groups (Lambert and Sevak 1996). However, such frameworks are only likely to be inclusive if policymakers engage with those groups that appear to experience most disadvantage. As highlighted in Chapter 8, the balance between different types of capital may need to be considered carefully and the views of Pakistani Muslims are likely to bring fresh perspectives to such debates. Policies that do not undermine the values and beliefs of Muslim communities and that have cross-cultural resonance are indicated as a way forward for service development. Research in health-related areas has emphasised the need for this collaborative approach (Farnell et al 2003).

This section has emphasised the need for policy development to prevent health inequalities in current and future generations of the Pakistani community. The following section suggests ways in which service providers can use existing policy in a more targeted way to address these inequalities in practice.

9.2 Implications for practice

A number of studies on race equality and cultural competence highlight similar issues to those raised in this research and offer approaches that could address the problems described. The Audit Commission's report on achieving race equality in local services offers a number of principles that have helped the development of inclusive service frameworks between providers and users. Echoing points raised in the previous section, the need to develop a shared vision and partnership with people from minority ethnic communities is emphasised (Audit Commission 2004).

Not surprisingly, given that the report's frame of reference is compliance with the Race Relations (Amendment) Act (HMSO 2000a), which does not protect Muslim communities from discrimination, there are few references to religion, faith or spirituality. However, examples of good practice offered include Lewisham's equality and diversity plan, which sets out a strategic approach to discrimination on the basis of race, age, gender, disability, religion and sexual orientation. Community engagement and wellbeing are described as the driving force for race equality initiatives in the borough. This approach accords with findings from this thesis and from recent studies of health inequality and of ethnicity, that the experience of discrimination is the key issue to be addressed and that individuals may be subject to this in relation to different and multiple aspects of their identity.

Betancourt et al (2002) review the work of organisations attempting to practice cultural competence in order to define its components. Again, although the report makes only passing reference to religious identity, its description of cultural competence suggests that this concept could be used to effectively overcome the disadvantage currently experienced by Pakistani people with chronic illness. This suggests again that actions to address discrimination can work across disadvantaged groups. Suggested actions, for example, include the development of tools to assess the health beliefs and behaviours of people from minority ethnic communities, as well as workforce and leadership that reflects diverse populations (Betancourt et al 2002). Systems of care designed around the needs of service users and good communication between providers and service users are further highlighted as vital components of cultural competence (ibid).

A review of ethnic disparities in health and healthcare (Aspinall and Jackson 2004) also offers some good practice examples demonstrating that, despite its absence from policy, religious identity is sometimes taken into account in the way services engage with communities and in the way services are delivered. 'Patient profiling', for example, may involve gathering information on ethnicity, country of birth, religion and language in order to develop information that might be useful in service delivery to individuals. However the review notes that the good practice examples offered are vignettes rather than properly evaluated accounts, descriptive rather than analytical and that they inform about process rather than outcomes. The need to evaluate systematically and independently, rather than through project staff, is emphasised, to identify features of good practice in relation to funding, staff, organisation, duration and objectives that are transferable.

Findings from this study confirm that steps to improve the management of chronic illness within the Pakistani community need to address a range of issues and be strategic rather than adopting a piecemeal approach. This study adds to existing research on race equality and cultural competence by indicating that attention to the faith beliefs of people from this community will form an important cornerstone for service development in all the areas highlighted as relevant. The particular ways in which the disadvantage experienced by Pakistani people with chronic illness can be addressed in practice are discussed below in relation to outcomes that have been indicated as central issues for people from this group.

9.2.1 Achieving shared understanding

Evidence-based training has been highlighted as a means of raising awareness about relevant socioeconomic factors that may apply to a community and the communication skills needed to interact effectively (Betancourt et al 2002). Training is also recommended to increase the confidence of service providers to engage with people from minority ethnic communities (Audit Commission 2004). The need for adequate resources to deliver training that is integrated into existing programmes has also been emphasised (Aspinall and Jackson 2004; Betancourt et al 2002).

Findings from this study indicate the kind of training that will develop practitioners' confidence to engage with Pakistani people with chronic illness, in order to develop concordant relationships. Given the central significance of religious beliefs and practices to many patients, the impact of this particular sphere on self-care needs to be understood in more than a superficial way. The findings show, for example, that religious practices such as prayer and fasting may have a significant influence on the way in which patients take medication and other decisions about how to manage their health. At the same time, factors associated with ethnicity, such as the increased likelihood of spending long periods abroad, are also relevant. Training will need to address how to create opportunities to discuss the impact of these influences on self-care in practitioner-patient consultations. The importance of challenging stereotypes and myths and ensuring that such training is evidence based is clearly crucial. Widening the parameters of professional knowledge will also require the active involvement of people who can challenge inaccurate notions that may dominate professional thinking (Dyson 1999).

Information about religious teachings on a particular subject offers a structured way of finding out some of the health beliefs that exist in this social group. Awareness of how these teachings interact with ethnic traditions in the lived experience of Muslims would develop a more sophisticated knowledge in practitioners. Findings suggest that developing this general understanding would allow practitioners to engage with patients more effectively than at present. Professionals, like people with chronic illness, may need to move from general information to specific knowledge that is relevant to a particular situation. This general knowledge is a first step to finding out about the way individual Pakistani people with chronic illness may manage their condition. Its value lies in enabling

professionals to ask sensible questions that further the potential for shared understanding. In addition, in the context of the diversity that exists within Pakistani communities, general knowledge of religious teachings may increase professional confidence to explore an individual's management of his or her condition. The creation of a 'safe environment' in which to develop this general knowledge and in which such questions could be tested is an important aspect of such training programmes (Audit Commission 2004).

This kind of knowledge is also relevant to broader health promotion work within the Pakistani community, such as healthy eating campaigns, which may need to address conventional practices that combine religious and ethnic traditions. The study suggests that differentiating between religious duties and ethnic traditions can help health professionals and members of the Pakistani community find common ground, which has emerged as an important theme. For example, findings demonstrate that social dynamics between hosts and guests, which are promoted by religious teachings, are interpreted in particular ways within the Pakistani community. Negotiating ethnic traditions of offering fried and sweet food in social situations is likely to be more effective if religious teachings about hospitality, for which support is likely to be strong, are accommodated in the health messages promoted.

Inability to differentiate between ethnic and religious norms may result in professionals ignoring these norms or else feeling that none are negotiable. Approaches to healthcare will consequently alienate communities or else fail to tackle serious health issues that need to be addressed. In either case, engagement will not take place. Whilst recognising that, for some Pakistani people, religious and ethnic identity are not differentiated, it is important to acknowledge the strong distinction made by others, for whom scriptural authority is paramount. Furthermore, confusion about conflicting practices, which may all be defined as Islam, is more easily dispelled when this distinction is made. Awareness that non-religious frameworks may also be used in decision-making and that diverse interpretations of scriptures can lead to diverse practice adds further sophistication to this understanding.

In this context, training can help identify reasons why Pakistani people with chronic illness may not be following professional advice and allow discussion of alternatives that are generally acceptable to both health professionals and members of the Pakistani community.

Staff development programmes that increase the confidence of practitioners and their awareness of patients' needs are likely to also contribute to a cultural shift within healthcare settings and more willingness to engage with people from Pakistani communities (Audit Commission 2004).

The evidence suggests that interpreters could contribute informal, regular and contextualised training through a wider role as 'cultural brokers' between patients and professionals. Drawing on minority ethnic staff as a valuable source of information and knowledge is promoted in existing studies as a way of achieving the cultural shift necessary within organisations (Audit Commission 2004). Findings from this study demonstrate that this role would be particularly valuable to Pakistani people with chronic illness in terms of additional explanation and reinforcement of professional advice as well as in terms of advocacy and having their own voice heard.

Using interpreters to develop the confidence of people with chronic illness and professionals from different cultural backgrounds to interact is likely to increase shared understanding and improve health outcomes. However, racism towards minority ethnic staff members is an issue that needs to be addressed if the resources they bring to services are to be fully utilised (Burford et al 2000). This study has shown that valuable resources aimed at improving service delivery to Pakistani people with chronic illness are often wasted because of poor understanding of how such staff can most effectively be deployed. Findings indicate the need for support networks to be set up and for clear remits to be worked out for these staff members before they are appointed.

Attention to language support remains a basic but vital access issue for many Pakistani people with chronic illness. Evidence from this study suggests that the culture within primary and secondary care clinics needs to be developed so that practitioners make regular use of bilingual service staff to meet patients' needs as well as their own. Changes in the way professional language support is organised are needed, to address not only how the service could be more easily accessed by professionals, but also how opportunities to deny access for patients can be reduced.

These arrangements need to be negotiated within services and involve reshaping organisational culture. For example, people with chronic illness would be more

empowered to request interpreting if services were advertised via appointment letters and visible notices in clinics. Delays affecting practitioners might be avoided by organising appointments requiring language support to fall on the same day, so that an interpreter is available to support a number of people throughout a clinic. However, simple rearrangements such as these are likely to be hindered more by a culture of resistance to accommodating the needs of Pakistani people, rather than a lack of imagination about how these needs can be met. Resistance to change may block effective implementation of policies aimed at achieving cultural competence; this suggests that addressing the culture within healthcare settings, through training and raising awareness, may need to be the first step for change management.

Professional capacity to allow time for interactions in which shared understanding can develop is clearly an issue for healthcare practitioners. However, findings suggest that the short term gains achieved by failing to address these issues may have long-term implications for time and resources as patients are exposed to a high risk of complications because of poor self-care. Identifying individuals who are particularly at risk of complications may be one way of achieving a balance in this respect. For example, professionals may need to identify instances of poor family support for patients. Where family dynamics are an obstacle to lifestyle change, targeted intervention that increases effective management, and reduce future complications may be necessary. The investment of time to discuss these dynamics is likely to be an effective use of NHS resources.

Capacity to engage with members of the Pakistani community is likely to be further enhanced by the appointment of more medically qualified and bilingual Pakistani professionals within healthcare services. Such professionals can help increase direct communication between patients and practitioners, improve understanding of cultural influences within healthcare teams and allow more informal access to advice and information with Pakistani communities. As with all practitioners, however, cultural competence should not be assumed and training may be necessary, particularly to increase awareness of social class discrimination and mechanisms for addressing racism and bias (Betancourt et al 2002). Managers responsible for appointing staff members are likely to need a more sophisticated awareness of diversity to ensure they make informed decisions. Findings indicate that regional diversity and prejudices that may exist within the Pakistani

community and between ethnic groups are likely to be relevant when appointing staff to reflect local populations.

9.2.2 Collaborative partnerships

Betancourt et al (2002) identify ongoing collaboration with community-based organisations as a vital element of cultural competence and a way of bringing the principles and perspectives of community-orientated care into mainstream systems. In line with the broader literature on health inequalities (see previous section) partnerships that promote the broadest possible definition of health and wellbeing are considered most effective in achieving better health outcomes.

Findings for this thesis show that partnerships between statutory and community organisations to improve health outcomes for Pakistani patients may not exist. Targeted interventions, such as Health Action Zone initiatives aimed at prevention of chronic illness, are delivered by community organisations with expertise in developing accessible and appropriate programmes. However, the learning from these initiatives may have no impact on primary or secondary care health services and their potential for supporting the self-care of people diagnosed with a chronic illness may remain unrealised. Projects are generally short-term and small scale and do not have the resources to reach the majority of Pakistani people.

The findings suggest that, in line with Government recommendations (Bauld and Judge 2002), these initiatives need to be part of a structured approach and linked to statutory services. Formal links, which improve the quality of service in both areas, are essential if such interventions are to have a lasting impact. The findings show that people with chronic illness and carers need greater access to qualified staff for advice and information that supports chronic illness management between primary and secondary care appointments. Collaborations between community-based projects and healthcare providers have the potential to help people with chronic illness avoid gaps in treatment and build up their knowledge of self-care. Evidence from this study suggests that partnership projects should aim to develop staff members who are knowledgeable about chronic conditions, culturally competent and able to advocate on behalf of patients.

Findings also indicate that collaboration on training programmes by voluntary and statutory services are likely to support better quality provision in both areas. Staff in

primary and secondary healthcare services need training in cultural influences on self-care whilst staff in voluntary organisations need better management and evaluation structures, as well as opportunities for skills training and career development. Expertise in each of these areas of work is almost entirely located in one sector, indicating that these areas should be priorities for collaboration between the two parts of service provision.

9.2.3 Empowerment

High levels of patient satisfaction and patient empowerment alongside good clinical outcomes are noted as important features of culturally competent organisations (Betancourt 2002). The evidence from this study suggests that service responses to complaints from members of the Pakistani community have not yet become a powerful means of achieving service development. Not only is the procedure inaccessible to many people, but people with chronic illness and carers lack confidence in the impartiality of the complaints system. Findings suggest that this lack of confidence is to some extent justified.

Defensive responses to complaints leave individuals feeling vulnerable and powerless and do not encourage professionals to identify areas for service development. The evidence suggests that a cultural shift is needed in complaints procedures if these are to be capable of stimulating organisation change. A responsive and collaborative approach, and more support to make complaints, is likely to increase the confidence of Pakistani people with chronic illness and improve the quality of healthcare services.

The issue of how seriously complaints are taken may be related to a wider problem. The credibility of individuals and groups within the Pakistani community is undermined by widespread negative stereotypes about Muslims and Islam. These stereotypes are likely to have an effect, which may at times be unconscious, on interactions between Pakistani individuals and practitioners in health and social care settings. For example, this study provides evidence that a Pakistani person's self-report about pain or symptoms of illness is not always readily accepted by health professionals. This dynamic has been reported to a limited extent in the wider literature on chronic illness, in cases where symptoms cannot readily be identified by professionals (Mann 2003) and in relation to older patients, who may experience discrimination in terms of being offered pain relief (Turner et al 1999). It is possible that such discrimination may play a part in professional unwillingness to fully accept self-reports of pain and may contribute to the delayed diagnoses that have been

documented in studies of Pakistani patients (Ahmad 2000). Training for health professionals that challenges such stereotypes is likely to strengthen the social position of Pakistani patients. This is a necessary step to increasing their confidence to engage with healthcare providers and to persist in having their concerns taken seriously.

There is currently little to counter the expectation - held by professionals and Pakistani people with chronic illness alike - of poor communication as a consequence of differences in cultural background. Findings suggest that the expectations of Pakistani patients about the cultural competence of healthcare staff need to be raised. This clearly must be attempted alongside initiatives that do increase the cultural competence of staff. Leadership and commitment at a senior level to such initiatives have been recognized as key factors for their success (Audit Commission 2004). Initiatives aimed at empowering the general population, such as the 'Expert Patient' programme, will also need to be targeted to reach Pakistani people with chronic illness who do not appear to be participating in such programmes despite their obvious relevance. Raising expectations within the Pakistani community is likely to increase empowerment and, consequently, activism, which has been identified as a facilitator of cultural competence in managed care (Betancourt et al 2002).

Evidence exists that the context in which particular types of topic are discussed and the presumed relationship with others present will affect how much individuals from different cultural backgrounds feel able to express (Niikura 1999). Findings from this thesis confirm that communication between Pakistani people with chronic illness and others in UK society, including health practitioners, is corrupted by dominant social norms that devalue religion in general and Muslim identity in particular. Initiatives that aim to train health professionals and raise the expectations of people with chronic illness need to take account of this context.

For intercultural understanding between religious and secular frameworks to develop, there is a need to take both seriously, rather than stereotyping the former as superstition and the latter as a mask for expediency (Currie 1991). Changes in healthcare practice will not be widely adopted without prior changes to social policy on health inequalities both frameworks. The first section of this Discussion highlighted what changes are needed; how such change might occur is dealt with in the following section.

9.3 Implications for research and for the Pakistani community

Findings from this thesis highlight the difficulty Pakistani respondents experience, both at an individual and collective level, in upholding religious values in the UK's predominantly secular society. Because these values are regularly undermined, individuals and groups within Pakistani communities⁷⁷ necessarily balance the need for self preservation against the need to engage with those from other social groups. The importance of support from social policy to counter these dynamics is demonstrated in this thesis and this section considers how such support can be gained, both through evidence generated by the research community and by activism by and on behalf of the Pakistani community.

Exworthy et al (2003) apply the 'policy windows' model to explain how social policies on health inequality have been formulated and implemented in the UK. This is a helpful framework in which to consider the prerequisites for faith identity to receive the support of social policy. According to this model, the three areas of evidence, policy and politics need to converge in order for policy windows to open. An evidence base needs to be developed that demonstrates the issue as a 'policy problem'. Strategies advanced by stakeholders inside and outside government are selected by policymakers if they are amenable to policy interventions, congruent with dominant values and able to confront future constraints such as changes in government. The process is a political one in which bargaining, negotiation and compromise between interest groups and power bases takes place. When evidence, policy and politics converge, often aided by 'natural cycles', such as elections, or by a 'policy entrepreneur', opportunities for change are created. When these three areas are separated, change is less likely.

Applying this model to faith identity and health inequalities in the Pakistani community highlights a number of problems and possible opportunities. Evidence relating faith identity to the social determinants of health such as unemployment and social exclusion is likely to be buried within research studies adopting the conceptual framework of ethnicity (see Chapter 3). However, some evidence for the feasibility of faith-based interventions does exist (Beckerleg 1995; Mir and Tovey 2003) and there is a growing literature that highlights the significance of discrimination against Muslims to determinants of health such

⁷⁷ see Chapter 8 for how this term has been defined in relation to this study

as social inclusion and civic participation (Commission on British Muslims and Islamophobia 2004; Muslim Council of Britain 2002b). The inclusion of a question on religious identity in Census 2001 has also resulted in data that supports further research into the links between faith identity and health and demonstrates its relevance (see Chapter 4).

Some detailed analysis of Census data on demography and social capital in Muslim communities in the UK is being carried out⁷⁸ and the Office for National Statistics has been urged to produce a multi-source topic report on religion by national Muslim organisations (Muslim Council of Britain 2002a; Forum Against Islamophobia and Racism 2002)⁷⁹. The overlap between faith identity and ethnicity, which is a more accepted framework in social policy, is acknowledged in these analyses and may help rally support, particularly as the distinction between religion and ethnicity is still blurred in social policy. Analysis of differences within the ethnic groups that make up the UK Muslim population could be helpful in identifying particular communities that experience multiple disadvantages in relation to the determinants of health.

Common ground between Islamic values and dominant values in UK policy will also need to be identified and a process for developing inclusive value frameworks negotiated. Congruence appears to exist in relation to Muslim youth, who are already perceived as a 'policy problem' for social cohesion, although the processes by which they are dealt with offer substantial evidence of discrimination (Allen 2002). Pakistani communities are also concerned about increasing delinquency amongst their youth and see greater involvement in community faith activity as a solution (Lewis 1994). There is already some evidence that faith interventions can be used to counter drug use and engage young Muslim men in positive ways within their communities (Beckerleg 1995). The wider literature on faith confirms findings from this study that religious values can strengthen family relationships (AddHealth 2004) and suggests that religiosity is a protective factor against youth delinquency (Regnerus 2003). Increasing interest in the relationship between spirituality and health in the wider literature (Speck et al 2004) also offers support to encourage policy development in this area.

⁷⁸ See <http://www.bristol.ac.uk/sociology/leverhulme/>

⁷⁹ To date, the Office of National Statistics has not produced this report but has widened its report on ethnicity to include some analysis of data on religion (Office of National Statistics 2004a).

Further congruence is suggested in literature on socio-economic position and health inequalities. The culture of accumulation encouraged by government economic policies has been presented as a causal factor for health inequalities and a reason for the vast socio-economic differences between different groups in the UK (Scambler 2002). Criticism of this value framework reflects criticism of materialism by Pakistani respondents in this study. Views that caring relationships are adversely affected by greater employment levels in the community are also suggested by this study and suggest the need for research to determine the appropriate balance between material, social and psychological capital.

Much of the initiative to challenge Islamophobia in the UK has come from Muslim communities themselves (Commission on British Muslims and Islamophobia 2004). The further challenge for Pakistani Muslim communities and those who aim to give them a voice, is, first, to gather evidence about the relevance of faith identity to social policy. In addition, there is a need to identify and develop areas of policy where congruence can be achieved between dominant values in the UK and the values inherent in Islam. This thesis suggests that such common ground is an important foundation for social cohesion involving Pakistani Muslim communities. The process of developing these areas is a political one; evidence from this study indicates that the attempt itself is likely to provoke resistance not only from within the majority ethnic and religious group in the UK but also from other religious minorities. Political assertiveness by Muslims in Britain is rejected by some specifically in relation to Islam, and by others because it is a religious identity and therefore considered irrelevant to the public sphere (Modood 2001). The 'critical mass' of civil servants and Ministers needed across government (Exworthy et al 2003) to acknowledge and address the relationship between Muslim identity and health inequalities is as yet unformed.

Nevertheless, there is evidence that national Muslim organisations, such as the Muslim Council of Britain and the Forum Against Islamophobia and Racism are adopting a leadership role in this respect and engaging with the political process in ways that are intended to inform policy⁸⁰. This activity is being supported by coalitions at a national and local level that establish common ground and develop joint projects (Muslim Association of Britain 2004; Muslim Council of Britain 2002b; 2004). Further research that contributes

⁸⁰ see, for example, Muslim Council of Britain (2004) and Forum Against Islamophobia and Racism (2004)

to the evidence base and to examples of the 'technical feasibility' of faith-based interventions (Exworthy et al 2003) are needed.

This thesis suggests that debates will take place within the Pakistani community as well as outside it about whether and how Muslim identity should be incorporated in decisions relevant to social policy. For example, not all Pakistani respondents in the sample felt the same way about how far Islamic principles should be incorporated into policy decisions relating to healthcare, employment and education. The need for coalitions between Muslims and other social groups is debated, not only in Muslim communities but amongst those with whom coalitions are formed (World Socialist Website 2004; Muslim Council of Britain 2002).

This diversity is to be expected in any community; nevertheless there is evidence that diversity amongst Muslim groups may be subject to intolerance. Attempts may be made to single out particular interpretations or ways of practising Islam as the only reasonable or moderate form with which engagement can take place (Alibhai-Brown 2002). Such arguments are common even in literature that purports to uphold the rights of Muslim populations (Geaves 1995; Lewis 1994), and continue the Orientalist tradition of promoting Muslim stereotypes and treating Islam, or at least some of its interpretations, as an inferior culture.

Findings from this study confirm existing evidence that Islamophobia has become an acceptable form of racism for a significant number of people in the UK (Sheridan 2002). Those who strongly oppose socio-economic and other inequalities in UK society may nevertheless uphold discrimination against Muslim communities (Toynbee 2003; 2001). Islamophobia may be fuelled even by those who oppose this kind of discrimination, if they deny legitimacy to diverse interpretations of Islam. Attempting to place restrictions on an individual's right to practice Islam to the extent he or she chooses within the law, and to stigmatise particular interpretations of Islam, is likely to radicalise Muslim communities, particularly if legal boundaries are developed without the involvement of a majority of Muslims.

This study suggests that the most lax and the most devout of Pakistani Muslims must be able to find a valued place within his or her community and within UK society as a whole.

Until this happens, disparities in the psychological and material wellbeing that is so vital to health will continue to disadvantage people from Pakistani communities and contribute to health inequalities that are both 'avoidable and unjust' (Department of Health/HM Treasury 2002).

REFERENCES

- Acheson Sir Donald (Chair) 1998, *Independent Inquiry into Inequalities in Health* The Stationery Office, London. <http://www.archive.official-documents.co.uk/document/doh/ih/part2h.htm> (Accessed June 2004)
- AddHealth 2004. The National Study of Youth and Religion. www.youthandreligion.org . 2004. (Accessed June 2004)
- Agadjanian V 1996, *Religion, Women's Identities and Childbearing in Urban Africa* American Sociological Association.
- Ahmad W, Kernohan E M, and Baker M R 1991, "General Practitioners' Perception of Asian and Non-Asian Patients", *Family Practice*, vol. 8, no. 1.
- Ahmad W 1996, "The Trouble with Culture," in *Researching Cultural Differences in Health*, Kelleher D and Hillier S, eds., Routledge, London. pp190 - 219
- Ahmad W 1999, "Ethnic Statistics: Better than Nothing or Worse than Nothing," in *Statistics in Society*, Dorling D and Simpson S, eds., Arnold. pp 124 - 131
- Ahmad W, Atkin K, and Jones L 2002, "Being deaf and being other things: young Asian people negotiating identities", *Social Science and Medicine*, vol. 55, no. 10, pp. 1757-1769.
- Ahmad W (ed) 2000, *Ethnicity, Disability and Chronic Illness* Open University Press, Buckingham.
- Ahmed A 2000, "Health and Disease: an Islamic Framework," in *Caring for Muslim Patients*, Sheikh A and Gatrad A R, eds., Oxon, pp. 29-39.
- Al A'ali 1993, "Assumptions Concerning the Social Sciences: A Comparative Perspective", *The American Journal of Islamic Social Sciences*, vol. 10, no. 4, pp. 485-490.
- Al Dabbagh A 1993, "Islamic Perspectives on Social Work Practice", *American Journal of Islamic Social Sciences*, vol. 10, no. 4 pp 536 -537
- Al Kanadi A B M 1991, *The Islamic Ruling on Music and Singing* Abul Qasim Bookstore/Saheeh International, Jeddah Saudi Arabia.

-
- Al Rashid M 2002, "Legal Developments since September 11: A Short Survey," in *Quest for Sanity*, Muslim Council of Britain, ed., Muslim Council of Britain, Middlesex.
- Ali M M 1990, *Guide to An Nawawi's 40 Hadith* JIMAS, Suffolk.
- Alibhai-Brown Y A. "Reformist Muslims are bringing new hope to Islam". Independent Newspaper 9th September 2002.
- Allen C 2002, "Islamophobia in the EU post-September 11," in *Quest for Sanity*, Muslim Council of Britain, Wiltshire.
- Anwar M 2003, "Socio-economic Position," in *British Muslims*, Seddon M S, Hussein D, and Malik N, eds., Islamic Foundation and Citizen Organisation Foundation.
- Asad T 1993, *Genealogies of religion : discipline and reasons of power in Christianity and Islam* Johns Hopkins University Press, Baltimore.
- Aspinall P and Jackson B 2004, *Ethnic Disparities In Health and Health Care: A focused review and selected examples of good practice* Department of Health/London Health Observatory, London.
- Assar, K. 1998, "Neighborhood and Islam", *International Sociological Association*.
- Atkin K and Ahmad W 1998, "Genetic counselling and haemoglobinopathies: ethics, politics and practice", *Social Science and Medicine*, vol. 46:3, pp. 445-458.
- Atkin K and Ahmad W 2000, "Family Caregiving and Chronic Illness: How parents cope with a child with a sickle cell disorder or thalassaemia", *Health and Social Care in the Community*, vol. 8, no. 1, pp. 57-69.
- Atkin, K., Ahmad, W. I. U., and Anionwu, E. W. 2000, "Service support to families caring for a child with a sickle cell disorder or beta thalassaemia major: parents' perspectives," in *Ethnicity, Disability and Chronic Illness*, W. I. U. Ahmad, ed., Open University Press, Buckingham pp103-122
- Audit Commission 2004, *Journey to Race Equality: Delivering improved services to local communities*, Audit Commission, London.

-
- Auluck R and Iles P 1991, "The Referral Process - A Study of Working Relationships Between Antenatal Clinic Nursing Staff and Hospital Social-Workers and their Impact on Asian Women", *British Journal of Social Work*, vol. 21,1, pp. 41-61.
- Barnes C 1996, "Disability and the myth of the independent researcher", *Disability and Society*, vol. 11 (1), pp. 107-110.
- Barot R (ed) 1993, *Religion and Ethnicity: Minorities and Social Change in the Metropolis* Kok Pharos, Kampen, The Netherlands.
- Bauld L and Judge K (eds) 2002, *Learning from Health Action Zones* Aenas Press, Chichester.
- BBC News 2002. Is language key to ethnic integration? news.bbc.co.uk/1/hi/uk/2261239.stm
- Beckerleg S 1995, "'Brown Sugar' or Friday Prayers: Youth Choices and Community Building in Coastal Kenya", *African Affairs*, vol. 94, no. 374, pp. 23-38.
- Betancourt J R, Green A R, and Carrillo J E 2002, *Cultural Competence In Health Care: Emerging Frameworks And Practical Approaches* The Commonwealth Fund.
- Bhakta P, Katbamna S, and Parker G 2000, "South Asian carer's experiences of primary health care teams," in *Ethnicity, Disability and Chronic Illness*, Ahmad W, ed., Open University Press, pp. 123-139.
- Bhopal R 1997, "Is research in ethnicity and health racist, unsound, or important science?", *BMJ*, vol. 314:1751, no. 14 June.
- Bhopal R and Rankin J 2002, "Concept and terminology in ethnicity, race and health: be aware of the ongoing debate ", *British Dental Journal*, vol. 186:10.
- Birke, L. & Whitworth, R. 1998, "Seeking Knowledge: Women, Science, and Islam ", *Women's Studies International Forum*, 1998, 21, 2, Mar-Apr, 147-159., vol. 21 Mar-Apr, no. 2 pp. 147-159.
- Bowes A and Domokos T 1996, "Pakistani women and Maternity Care: raising muted voices", *Sociology of Health and Illness*, vol. 18, 1, pp. 45-65.
- Bowler I 1993, "Stereotypes of women of Asian descent in midwifery: some evidence", *Midwifery*, vol. 9, pp. 7-16.

- Bradford Metropolitan City Council (2005) *Calendar of Religious Festivals 2005*
http://www.abi.co.uk/index.php?option=com_docman&task=doc_download&gid=48&Itemid=110&mode=view (Accessed April 2005)
- British Council (2004) *Race and Ethnicity: Economic Activity*
http://www.britishcouncil.org/diversity/race_population.htm#Initial (Accessed April 2005)
- British Medical Association 1995, *Multicultural health care : current practice and future policy in medical education*, BMA, London.
- Bryman A and Burgess R 1994, *Analysing Qualitative Data*, Routledge, London.
- Buaras E A. 2003 "Pork in halal chicken". The Muslim News Issue 168, 23 Safar 1424
- Burford B, Bullas S, and Collier B 2000, *Positively Diverse Report 2000* Department of Health/NHS Executive.
- Burgess R G 1984, *In the field : an introduction to field research* Allen and Unwin, London.
- Burns J. "Blunkett voted most Islamophobic". Financial Times Newspaper 30th May 2003.
- Bury M 1982, "Chronic Illness as Biographical Disruption", *Sociology of Health and Illness*, vol. 4, no. 2, July, pp. 167-182.
- Cesari J 1998, "Muslim Representation in a European Political Context ", *Encounters*, vol. 4,2, no. 149, p. 155.
- Chamba R, Ahmad W, and Jones L 1998, *Improving Services for Asian Deaf Children* Policy Press, Bristol.
- Chamba, R. and Ahmad, W. I. U. 2000, "Language, communication and information," in *Ethnicity, Disability and Chronic Illness*, W. I. U. Ahmad, ed., Open University Press, Buckingham pp 85-102
- Chandola T, Kuper H, Sing-Manoux A, Bartley M, Marmot M (2004) "The effect of control at home on CHD events in the Whitehall II study: gender differences in psychosocial domestic pathways to social inequalities in CHD". *Social Science and Medicine* 58 (8) pp 1501-9

Charmaz K and Olesen V 1997, "Ethnographic research in medical sociology - its foci and distinctive contributions", *Sociological Methods and Research* 1997, vol. 25, 4, pp. 452-494.

Chaudhary L N 1997, "Researching "my people," researching myself: fragments of a reflexive tale", *International Journal of Qualitative Studies in Education*, vol. 10, no. 4, pp. 441-453.

Cinnirella M and Loewenthal K M 1999, "Religious and ethnic group influences on beliefs about mental illness: A qualitative interview study", *British Journal of medical Psychology*, vol. Vol 72, no. 4, pp. 505-524.

Commission for Racial Equality 1998, *Stereotyping and Racism: Findings from two attitude surveys*, Commission for Racial Equality, London.

Commission on British Muslims and Islamophobia 2004, *Islamophobia - issues, challenges and action* Trentham Books, Stoke on Trent.

COREC (Central Office for Research Ethics Committees) 2004. 'New Operational Procedures for NHS Research Ethics Committees: Guidance for Applicants to RECs'. http://www.corec.org.uk/applicants/help/docs/Guidance_for_Applicants_to_RECs.pdf . (Accessed June 2004)

Currie P M 1991, "The Pilgrimage of Ajmer," in *Religion in India*, Madan T N, ed., Open University Press, Delhi pp 237-247.

Denzin N K 1989, *The research act : a theoretical introduction to sociological methods* Prentice Hall, Englewood Cliffs, N.J; London.

Denzin N K and Lincoln Y S (eds) 1994, *Handbook of qualitative research* Sage, Thousand Oaks, California; London.

Department of Environment Transport and the Regions 1997, *Involving Communities in Urban and Rural Regeneration: a Guide for Practitioners*, DETR, London.

www.neighbourhood.gov.uk/displaypagedoc.asp?id=177

Department of Environment Transport and the Regions 2000, *Our Towns and Cities : The Future* (Cm 4911) London, The Stationery Office

-
- Department of Health. 1999 *Saving Lives - Our Healthier Nation* (Cm 4386). London, The Stationery Office.
- Department of Health. *The NHS Plan. A Plan for Investment. A Plan for Reform.* (Cmnd 4818-1) 2000. London, The Stationery Office.
- Department of Health (a) 2001, *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*, The Stationery Office, London.
- Department of Health (b) 2001, *National service framework for diabetes: standards*, Department of Health, London.
- Department of Health/HM Treasury 2002, *Tackling Health Inequalities: Cross Cutting Review*, Department of Health/HM Treasury.
- Department of Health (b) 2002, *National service framework for coronary heart disease : modern standards and service models*, Department of Health, London.
- Department of Health 2003, *Delivering Race Equality: A Framework for Action*, Department of Health, London.
- Department of Health and NHS Chaplaincy 2003, *Meeting the religious and spiritual needs of patients and staff*, Department of Health.
- Department of Health 2004. *Experiencing healthier lifestyles: Work to reduce health inequalities in local communities.*
http://www.dh.gov.uk/NewsHome/NewsArticle/fs/en?CONTENT_ID=4087445&chkmIUMd%2B (Accessed June 2004)
- Dhami S and Sheikh A 2000, "The Family: Predicament and Promise," in *Caring for Muslim Patients*, Sheikh A and Gatrad A R, eds., Radcliffe Medical Press, Oxon, pp. 43-56.
- Donnelly T T 2002, "Representing 'Others': avoiding the reproduction of unequal social relations in research [Post-Colonial Research]", *Nurse Researcher*, vol. 9, no. 3, pp. 57-67.
- Donovan J L and Blake D R 1992, "Patient Noncompliance - Deviance or Reasoned Decision-Making", *Social Science and Medicine*, vol. 34, no. 5, pp. 507-513.
- Drozdikova J 1999, "Islam in Unity and Diversity", *Human Affairs*, vol. 9,2, pp. 185-196.

- Dwyer C 1998, "Contested Identities: challenging dominant representations of young British Muslim women," in *Cool Places*, Skelton T and Valentine G, eds., Routledge, London pp 50-65
- Dyck I 1995, "Putting chronic illness in place: Women Immigrants' Accounts of their Health Care", *Geoforum*, vol. 26,3, no. 247, p. 260.
- Dyson S 1998, "'Race', ethnicity and haemoglobin disorders", *Social Science and Medicine*, vol. 47, no. 1, pp. 121-131.
- Dyson S 1999, "Review of *Human Genetics. Choice and Responsibility* by the British Medical Association, Oxford University Press 1998", *Social Science and Medicine*, vol. 49, no. 1425, pp 1427 - 1429.
- Exworthy M, Blane D, and Marmot M 2003, "Tackling Health Inequalities in the United Kingdom: The Progress and Pitfalls of Policy", *Health Services Research* vol. 38, no 6 pp. 1905-1922.
- Farnell R, Furbey R, Hill S S H, Macey M, and Smith G 2003, '*Faith' in urban regeneration? Engaging faith communities in urban regeneration*, JRF/The Policy Press.
- Farshi Z, Atkinson K, and Sleight J 1999, *Evaluation of the Leeds NHS Interpreting project*, Leeds Teaching Hospitals NHS Trust.
- Fisher B 2001, *Services for All* Association for Real Change, Derbyshire.
- Forum Against Islamophobia and Racism 2002, *Office for National Statistics Multi-Source Topic Report On 'Religion' - Scoping Note: A Response From The Forum Against Islamophobia and Racism (FAIR)*, FAIR, London.
- Forum Against Islamophobia and Racism.2004. www.fairuk.org (Accessed June 2004)
- Geaves R 1995, *Muslims in Leeds* Dept of Theology and Religious Studies, University of Leeds.
- Halliday F 1999, "'Islamophobia' Reconsidered", *Ethnic and Racial Studies*, vol. 22, no. 5, pp. 892-902.
- Hammersley M 1992, *What's Wrong with Ethnography* Routledge, London.
- Hammersley M and Atkinson P 1995, *Ethnography* Routledge, London.

-
- Harvey D (1990) *Critical Social Research* Hyman Unwin., London.
- Hatton C, Azmi S, Caine E, and Emerson E 1998, "Informal carers of adolescents and adults with learning disabilities from South Asian communities", *British Journal of Social Work*, vol. 28, pp. 821-837.
- Hatton C, Turner S, Shah R, Rahim N, and Stansfield J 2004, *Religious Expression, a fundamental human right: The report of an action research project on meeting the religious needs of people with learning disabilities* Foundation for People with Learning Disabilities.
- Health Development Agency 2004 www.hda-online.org.uk and www.modern.nhs.uk (Accessed June 2004)
- Henley, A. 1982, *Asian Patients in Hospital and at Home* Oxford University Press.
- Hill S A 1994, *Managing Sickle Cell Disease in Low Income Families* Temple University Press, Philadelphia.
- Hillier S 2001, "Book Review: *Ethnicity, Disability and Chronic Illness* by Ahmad W I U (ed)", *Sociology of Health and Illness*, vol. 23:4, pp. 541-542.
- Hirschfield A, Abrahams A, Barnes R, Hendley J, and Scott-Samuel A. 2001 *Health Impact Assessment: Measuring the Effect of Public Policy on Variations in Health - Executive Summary*. <http://www.ihia.org.uk/recentreportsbyimpact.html> (Accessed June 2004)
- HMSO 2000a. *The Race Relations (Amendment) Act: New Laws for a Successful Multi-racial Britain*. London: The Stationery Office
- HMSO 2000b. *The Terrorism Act*. London: The Stationery Office.
- Hofrichter R 2004, "The Politics of Health Inequities: Contested Terrain," in *Health and Social Justice: Ideology and Inequity in the Distribution of Disease*, Hofrichter R (ed), ed., Jossey Bass Wiley, pp. 1-56.
- Holdcroft A and Power I 2003, "Recent developments: Management of pain", *BMJ*, vol. 326, no. 635, p. 639.

-
- Holden C and Downie A 2002, "Evaluating the Evaluators: the role of evaluation in Health Action Zones; some lessons learnt," in *Learning from Health Action Zones*, Bauld L and Judge K, eds., Aenas Press, Chichester.
- Horn I B and Beal A C 2004, "Child Health Disparities: Framing a Research Agenda", *Ambulatory Pediatrics*, vol. July/Aug.4 (4), pp. 269-275.
- Huberman M and Miles M B 2002, *The Qualitative Researcher's Companion* Sage, Thousand Oaks.
- Hull J M 1999, "Spirituality, religion, faith: mapping the territory", *Youth and Policy*, vol. 65, pp. 48-65.
- Husain F and O'Brien M 1998, "South Asian Muslims in Britain: Faith, Family and Community", *International Sociological Association*.
- Hutchinson, G. and Gilvarry, C. 1998, "Ethnicity and dissatisfaction with mental health services", *British Journal of Psychiatry*, vol. Vol 172, pp. 95-96.
- Ibrahim E 1997, *An-Nawawi's Forty Hadith: An Anthology of the Sayings of the Prophet Muhammad* Intl Specialized Book Service Inc.
- Ibrahim I A 1997, *A Brief Illustrated Guide to Understanding Islam* Darussalaam Publishers, Houston.
- INVOLVE 2004. Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People .
<http://www.invo.org.uk/pdfs/Brief%20Summary%20and%20Checklist%20for%20Researcher%20rsver2.pdf> . (Accessed June 2004)
- Islamic Human Rights Commission. Press Release: Blunkett's Incitement Law Spells Danger for Ethnic Communities. <http://server792.dnslive.net/~ihrc/show.php?id=1129> . 7-7-2004.
Ref Type: Internet Communication
- Johnson V and Webster J 2000, *Reaching the Parts ... Community Mapping, Working Together to Tackle Social Exclusion and Food Poverty* Sustain; Oxfam, London.
- Karim, J. 1996, *Access to Accident and Emergency Services for Minority Ethnic Residents* Birmingham Heartlands and Solihull NHS Trust.

-
- Karlsen S and Nazroo J 2002, "Agency and Structure: The impact of ethnic identity and racism on the health of ethnic minority people", *Sociology of Health and Illness*, vol. 24, no. 1 pp1-20.
- Katbamna S, Bhakta P, and Parker G 2000, "Perceptions of disability and care-giving relationships in South Asian communities," in *Ethnicity, Disability and Chronic Illness*, Ahmad W, ed., Open University Press, pp. 12-27.
- Kaufert J 1999, "Cultural Mediation in Cancer Diagnosis and End of Life Decision-Making: The Experience of Aboriginal Patients in Canada", *Anthropology and Medicine*, vol. 6, 3, pp. 405-421.
- Kelleher D 1996, "A defence of 'ethnicity' and 'culture'," in *Researching Cultural Differences in Health*, Kelleher D and Hillier S, eds., Routledge, London, New York, pp. 69-90.
- Kelleher D and Islam S 1996, "'How Should I Live?': Bangladeshi people and non-insulin dependent diabetes," in *Researching Cultural Differences in Health*, Kelleher D and Hillier S, eds., Routledge, London and New York pp 220-237
- Khan, M. M. 1987, *The Translation of the Meaning of Sahih Al-Bukhari (Arabic-English); 9 Volumes* Darussalaam Publishers, Riyadh, Saudi Arabia.
- Kimberley A L, Kawachi I, Brennan R T, and Buka S L 2003, "Social Capital and Neighbourhood Mortality Rates in Chicago", *Social Science and Medicine*, vol. 56, no. 8, pp. 1797-1805.
- Kralik D, Kock T, and Brady BM 2000, "Pen pals: correspondence as a method for data generation in qualitative research", *Journal of Advanced Nursing*, vol. 31, 4, pp. 909-917.
- Lago C and Thompson J 1996, *Race, Culture and Counselling* Open University Press.
- Lambert, H. and Sevak, L. 1996, "Is 'cultural difference' a useful concept? Perceptions of health and the sources of ill health among Londoners of South Asian origin," in *Researching Cultural Differences in Health*, Kelleher D and S. Hillier, eds., Routledge, London and New York, pp. 124-159.

-
- Lawson L, Mackenzie M, Mackinnon J, Meth F, and Truman J 2003, *Health Action Zones: Integrated Case Studies: Preliminary Findings from Fieldwork in Spring 2001*, Glasgow University, Glasgow.
- Lewis P 1994, *Islamic Britain: Religion, Politics and Identity among British Muslims* I B Taurus, London, New York.
- Lewis R K, Lasack N L, Lambert B L, and Connor S E 1997, "Patient counseling - a focus on maintenance therapy", *American Journal of Health-System Pharmacy*, vol. 54, 18, no. 2084, p. 2098.
- Mahmood N and Ringheim K 1997, "Knowledge, Approval and Communication about Family Planning as Correlates of Desired Fertility among Spouses in Pakistan", *International Family Planning Perspectives*, vol. 23, 3, pp. 122-129.
- Mann E 2003, "Managing Pain", *BMJ*, vol. 326, no. 1320, p. 1321.
- Marmot M G 2004, *Status Syndrome - How Our Position on the Social Gradient Affects Longevity and Health* Bloomsbury.
- Marmot M G and Siegrist J. 2004 "Health inequalities and the psychosocial environment". *Social Science and Medicine* 58[8], 1461-1574.
- Marmot, M. G., Fuhrer, R., Ettner, S. L., Marks, N. F., Bumpass, L. L., and Ryff, C. D. 1998, "Contribution of psychosocial factors to socioeconomic differences in health", *Milbank Quarterly*, vol. 76 (3), pp. 403-448.
- Mason J 1996, *Qualitative Researching* Sage, London.
- Matsuoka A and Sorenson J 2001, *Ghosts and shadows: construction of identity and community in an African diaspora*. University of Toronto Press, London, Toronto.
- Medical News Today 2004. UK Dept of Health allocates £4.5 million to boost direct payments to 44 charities. <http://www.medicalnewstoday.com/newssearch.php?newsid=9486> (Accessed June 2004)
- Mellor P A 1993, "Reflexive Traditions: Anthony Giddens, High Modernity, and the Contours of Contemporary Religiosity", *Religious Studies*, vol. 29, no. 111, p. 127.

-
- Mir G, Tovey P, and Ahmad W 2000, *Cerebral Palsy and South Asian communities*, Centre for Research in Primary Care, University of Leeds.
- Mir G, Nocon, A., and Ahmad W 2001, *Learning Difficulties and Ethnicity*, Department of Health, London.
- Mir G and Tovey P 2003, "Asian Carers' Experience of Medical and Social Care: The Case of Cerebral Palsy", *British Journal of Social Work*, vol. 33, no. 465, p. 479.
- Mir G and Din I 2003, *Communication, Knowledge and Chronic Illness in the Pakistani Community*, Centre for Research in Primary Care, University of Leeds, Leeds.
- Mir, G., Nocon, A., and Ahmad W 2001, *Learning Difficulties and Ethnicity*, Department of Health, London.
- Modood T, Berthoud R., Lakey J, Nazroo J, Smith P, Virdee S, and Beishon S 1997, *Ethnic Minorities in Britain: Diversity and Disadvantage* Policy Studies Institute, London.
- Modood T 2001, "The Place of Muslims in Secular Multiculturalism in Great Britain", *Social Compass*, vol. 47, 1, pp. 41-55.
- Muhammadi A and Ahsan M 2002, *Globalisation or Recolonisation? The Muslim World in the 21st Century* Taha Publishers, London.
- Murphy, K. and Clark, J. 1993, "Nurses' experiences of caring for ethnic minority clients", *Journal of Advanced Nursing*, vol. 18, 3, pp. 442-450.
- Muslim Association of Britain 2004. <http://www.mabonline.info/campaigns> (Accessed June 2004)
- Muslim Council of Britain 2002a, *Response to the Office for National Statistics: Religion - Scoping Report*, MCB, London.
- Muslim Council of Britain 2002b, *The Quest for Sanity* Muslim Council of Britain, Middlesex.
- Muslim Council of Britain 2004. www.mcb.org.uk
- Muslim News 2000, *The Muslim News Awards for Excellence* Muslim News, London.

-
- National Primary Care Development Team 2003. *The First Two Years*. [http://www.npdt.org/1626/The First Two Years.pdf](http://www.npdt.org/1626/The%20First%20Years.pdf) . (Accessed June 2004)
- Naz Project London 2002, *Muslims, sexual health and HIV*, Naz Project London, London.
- Nazroo J 1997, *The Health of Britain's Ethnic Minorities* Policy Studies Institute, London.
- Nazroo J 1997, *Ethnicity and mental health : findings from a national community survey*, Policy Studies Institute, London.
- Nettleton S 1995, *The Sociology of Health and Illness* Polity Press, Cambridge.
- Niikura R 1999, "The psychological process underlying Japanese assertive behaviour: comparison of Japanese with Americans, Malaysians and Filipinos", *International Journal of Cultural Relations*, vol. 23,1, pp. 47-76.
- Novás J D and Sacasas J A F 2004. From Municipal Polyclinics to Family Doctor-and-Nurse Teams. *Cuban Medical Research* . 9th August 2004.
- Office of the Deputy Prime Minister 2004, *Involving Faith Communities*
www.neighbourhood.gov.uk/displaypagedoc.asp?id=177
- Office for National Statistics 2004. Census data <http://www.national-statistics.gov.uk>
(Accessed June 2004)
- Office for National Statistics 2004a. Census data <http://www.national-statistics.gov.uk/CCI/nugget.asp?ID=293&Pos=&ColRank=2&Rank=224> (Accessed June 2004)
- Office for National Statistics 2004b. Census data.
<http://www.statistics.gov.uk/CCI/nugget.asp?ID=348andPos=andColRank=2andRank=320>
(Accessed June 2004)
- Office for National Statistics 2004c. Census data
<http://www.statistics.gov.uk/cci/nugget.asp?id=465>. (Accessed June 2004)
- Office of the Deputy Prime Minister 1997, *Involving Communities in Urban and Rural Regeneration: a Guide for Practitioners* , The Stationery Office, London.

- Office of the Deputy Prime Minister 2000 *Our Towns and Cities: The Future* (Cmnd 4911) The Stationery Office, London
- Philips A.A.B 1995, *The Purpose of Creation* Dar al Fatah Publishers, UAE.
- Pickering M 1997, "A New Look at Auguste Comte ," in *Reclaiming the Sociological Classics - The State of the Scholarship*, Camic C, ed., Blackwell, pp. 11-14.
- Pickthall M M 2000, *The Meaning of the Glorious Qur'an: an explanatory translation* Islamic Dawah Centre International, Birmingham.
- Pierret J 1993, "Constructing Discourses about Health and their Social Determinants," in *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, Radley A, ed., Routledge pp 9-26
- R K Consultancy 1997, *Home Care Provision for Black Communities in Leeds* Leeds Involvement Project, Leeds.
- Radley A 1993, *Worlds of Illness: biographical and cultural perspectives on health and disease* Routledge.
- Ragab I 1993, "Islamic Perspective on Theory Building in the Social Sciences", *American Journal of Islamic Social Sciences*, vol. 10, no. 1 pp 1-22.
- Rankin J and Bhopal R 1999, "Current census categories are not a good match for identity", *BMJ*, vol. 318, no. 7199, p. 1696.
- Regnerus 2003, "Linked Lives, Faith and Behaviour: Intergenerational Religious Influence on Adolescent Delinquent Behaviour", *Journal for the Scientific Study of Religion*, vol. 42, no. 2, pp. 189-203.
- Rier D A 2000, "The missing voice of the critically ill: a medical sociologist's first-person account", *Sociology of Health and Illness*, vol. 22,1, pp. 68-93.
- Ritch A et al 2001, "Ethnic influence on health and dependency of elderly inner city residents", *Journal of the Royal College of Physicians of London*, vol. 30, no. 3, pp. 215-220.
- Ritchie J and Spencer L 1994, "Qualitative data analysis for applied policy research," in *Analysing Qualitative Data*, Bryman A and Burgess R, eds., Routledge, London, pp. 173-194.
- Robinson M 2002, *Communication and Health in a Multi-ethnic Society* Policy Press, Bristol.

-
- Rodrigo, L. and Munton, R. 2002, "Addressing Inequalities in Health: education and training as a catalyst for change and innovation," in *Learning from Health Action Zones*, L. Bauld and K. Judge, eds., Aeneas, Chichester, pp. 273-284.
- Rudat K 1994, *Black and Minority Ethnic Groups in England* Health Education Authority, London.
- Runnymede Trust (Commission on British Muslims and Islamophobia). 1997, *Islamophobia : a challenge for us all : report of the Runnymede Trust Commission on British Muslims and Islamophobia* Runnymede Trust, London.
- Rushdie S 2004, *The Satanic Verses*, Viking, London.
- Ryan M, Scott D A, Reeves C, Bate A, van Teijlingen E R, Russell E M, Napper M, and Robb C M. Eliciting public preferences for healthcare: a systematic review of techniques. *Health Technology Assessment* 5[5], 17-24. 2001.
- Rybarczyk, B., DeMarco, G., DeLaCruz, M., and Lapidus, S. 1999, "Comparing mind-body wellness interventions for older adults with chronic illness: Classroom versus home instruction", *Behavioral.Medicine*, vol. Vol 24, no. 4, pp. 181-190.
- Said E 1995, *Orientalism* Penguin Books, London.
- Scambler G 2002, "The New Inequality and Health," in *Health and Social Change*, Open University Press, Buckingham; Philadelphia, pp. 86-109.
- Schofield, J. 1993, "Increasing the generalisability of qualitative research," in *Social Research*, M. Hammersley, ed., Sage, London pp 200-225.
- Schott, J. and Henley, A. 1996, *Culture, Religion and Childbearing in a Multiracial Society* Butterworth Heinemann, Oxford.
- Selway D and Ashman A 1998, "Disability, Religion and Health: a literature review in search of the spiritual dimensions of disability", *Disability and Society*, vol. 13, pp. 429-439.
- Shah, A. and Piracha, A. H. (1993) *Hello, Can You Hear Me?* Public Health Promotion Unit, Blackburn, Hyndburn and Ribble Valley Authority
- Sheikh A and Gatrad A R 2000, *Caring for Muslim Patients* Radcliffe Medical Press.

-
- Sheridan L 2002, "Religious Discrimination: The New Racism," in *Quest for Sanity*, Muslim Council of Britain, ed., Muslim Council of Britain, Middlesex pp 86-93.
- Siddiqi A H (Translator) 2000, *Sahih Muslim Volumes I-IV by Imam Muslim*, Kitab Bhavan.
- Silverman, D. 1993, *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction* Sage, London.
- Smith C and Kim P 2003, *Family Religious Involvement and the Quality of Parental Relationships for Families With Early Adolescents*, National Study of Youth and Religion, North Carolina, 5.
- Smith C and Faris R. 2002 "Correlation found between Religion and Community Service". <http://www.youthandreligion.org/news/6-4-2002.html> (Accessed June 2004)
- Social Exclusion Unit. Review of the Social Exclusion Unit. 1997
<http://www.socialexclusionunit.gov.uk/downloaddoc.asp?id=241> (Accessed April 2005)
- Social Exclusion Unit 2001, *A New Commitment to Neighbourhood Renewal: National Strategy Action Plan*, The Cabinet Office , London.
- Social Exclusion Unit 2004a <http://www.socialexclusionunit.gov.uk> . (Accessed June 2004)
- Social Exclusion Unit 2004b. Jobs and enterprise in deprived areas: Scoping Note. <http://www.socialexclusionunit.gov.uk/downloaddoc.asp?id=77> (Accessed April 2005)
- Sonuga-Barke E J S and Mistry M 2000, "The effect of extended family living on the mental health of three generations within two Asian communities", *British Journal of Clinical Psychology*, vol. 39, pp. 129-141.
- Speck P, Higginson I, and Addington-Hall J 2004, "Spritual needs in healthcare", *BMJ*, vol. 2004, no. 329, pp. 123-124.
- Stevenson F A, Barry C A, Britten N, Barber N, and Bradley C P 2004, "Doctor-patient communication about drugs: the evidence for shared decision making", *Social Science and Medicine*, vol. 50, no. 6, pp. 829-840.
- Stevenson, F. A., Barry, C. A., Britten, N., Barber, N., and Bradley, C. P. 2000, "Doctor-patient communication about drugs: the evidence for shared decision making", *Social Science and Medicine*, vol. 50, 6, pp. 829-840.

-
- Strauss A 1987, *Qualitative Analysis for Social Scientists*. Cambridge University Press, New York.
- Stubbs P 1993, "Ethnically sensitive or 'anti-racist': models for health research," in *Race and Health in Contemporary Britain*, Open University Press, Buckingham; Philadelphia.
- Surty M 1995, *Halal Food in the Light of the Qur'an and Sunnah* Taha Publications, London.
- Taha A 1993, *Medicine in the Light of the Qur'an and Sunna* Taha Publications, London.
- Tetzlaff L 1997, "Consumer Informatics in Chronic Illness", *Journal of the American Medical Informatics Association*, vol. 4, no. 4, pp. 285-300.
- The Leeds Initiative 2003, *Census 2001:Leeds The Big Picture*, The Leeds Initiative, Leeds.
- Toynbee P 2001. "Keep God out of class". The Guardian Newspaper 9th November 2001.
- Toynbee P 2003, *Hard Work: Life in Low-pay Britain* Bloomsbury, London.
- Turner N J, Haward R A, Mulley G P, and Selby P J 1999, "Cancer in old age is it inadequately investigated and treated?", *BMJ* no. 319, pp. 309-312.
- Vangen, S., Stoltenberg, C., and Schei, B. 1996, "Ethnicity and use of obstetrical analgesia: Do Pakistani women receive inadequate pain relief in labour?", *Ethnicity and Health*, vol. Vol 1, no. 2, pp. 161-167.
- Versi A J 2003. BBC accused of inciting attacks against Muslims. The Muslim News 170 26 Rabi' al-Akhar 1424.
- Walker D 2002. Study reveals jobs plight of Muslims: Cabinet Office report highlights wide ethnic gap in jobs market. The Guardian Newspaper . 20-2-2002.
- Walsh F 1998, *Strengthening Family resilience* The Guildford Press, New York.
- Wheeler E 1998, "Mental Illness and Social Stigma", *Gender and Development*, vol. 6, 1, pp. 37-43.
- Whitaker B 2002, "Islam and the British Press ," in *The Quest for Sanity*, Muslim Council of Britain pp 53-57.

- Whitaker B 2002, "Islam and the British Press," in *Quest for Sanity*, Muslim Council of Britain, ed., Muslim Council of Britain, Middlesex.
- Wiles R 1998, "Patients perception of their heart attack and recovery: the influence of epidemiological 'evidence' and personal experience", *Social Science and Medicine*, vol. 46, no. 11, pp. 1477-1486.
- Williams G 1993, "Chronic Illness and the Pursuit of Virtue in Everyday Life," in *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, Radley A, ed., Routledge pp 92-108.
- Williams R 1993, "Religion and Illness," in *Worlds of Illness: biographical and cultural perspectives on health and disease*, Radley A, ed., Routledge, London and New York pp 71-91.
- Woods S E, Lake J R, and Springett J 2003, "Tackling health inequalities and the HAZ Smoking Cessation Programme: the perfect match?", *Critical Public Health*, vol. Volume 13, Number 1, pp. pp61-76.
- World Socialist Website 2004. <http://www.wsws.org/articles/2004/mar2004/wsws-m20.shtml> (Accessed June 2004)
- Wuerker A, Haas G L, and Bellack A S 1999, "Interpersonal control in families of persons with schizophrenia", *Family Process*, vol. 38, 4, pp. 477-496.
- Wuthnow R 1986, "Religion as Sacred Canopy," in *Making Sense of Modern Times: Peter L. Berger and the Vision of Interpretive Sociology*, Hunter J D and Ainlay S C, eds., Routledge and Kegan Paul, London, pp. 121-142.
- Yahya H 2004. *The Hypocrite According to the Qur'an*. Harun Yahya Publications. <http://www.harunyahya.com/books/faith/hypocrite/hypocrite1.php> (Accessed June 2004)
- Younge G. "Britain is again white: Thanks partly to Blunkett, the race debate has regressed in the three years since the Macpherson report" . The Guardian Newspaper 18th February 2002.

Appendix 1: Glossary

All words are from Arabic unless indicated otherwise	
ahadith	Plural of 'hadith': an account of a saying or action from the life of the Prophet Muhammad.
assalaamu alaykum	Literally 'Peace be upon you'. A religious expression used when greeting or parting from someone
biraderi	(Urdu) An extended kinship network, comprising individuals who are related through blood or marriage ties (see also Ahmad 1996).
hadith	An account of a saying or action from the life of the Prophet Muhammad.
hajj	The pilgrimage to Makkah in Saudi Arabia, which every Muslim is required to perform at least once in his or her lifetime
Hijab	Headscarf or covering worn by Muslim women
insha Allah	Literally 'God willing'. Usually used in references to events in the future
khuda hafiz	(Urdu) Literally 'God be with you'. Used when parting from someone.
masha Allah	Literally 'As God wills'. An expression showing approval
namaaz	(Urdu and Punjabi) Obligatory ritual prayer prescribed five times daily for Muslims in the Qur'an
pardah	(Urdu) Modest dress aimed at covering up the body
shalwar qamiz	(Urdu) traditional dress worn by Pakistani women consisting of a dress and loose fitting trousers
sunnah	The practical example of the Prophet Muhammad's life. His actions and directions are considered to be a source of authority for religious practice by most Muslims
taqwa	A state of God-consciousness attained through sincere submission to God and incorporation of Islam into everyday life
topi	Headcovering worn by Pakistani Muslim men, especially during prayer
ummah	The Muslim community. This can be understood at a local level or as the worldwide community of Muslims linked together by a bond of faith.

Appendix 2: Census Data

Table 5 - numbers of people from different faith communities in each socio-economic group

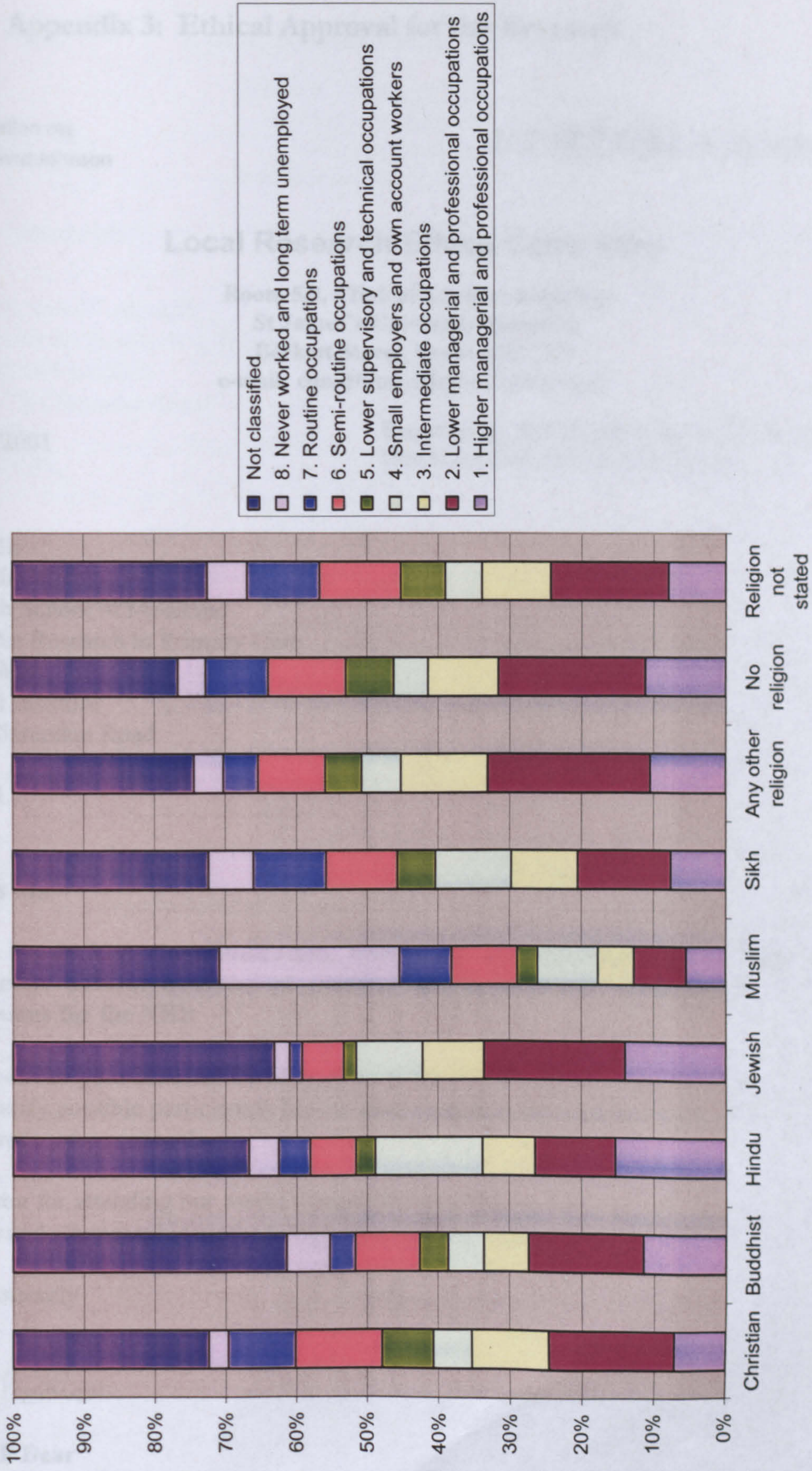
	Table population: All people aged 16 to 74										
	ALL PEOPLE	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Other religion	No religion	Not stated	
ALL PEOPLE	520,479	361,979	1,398	3,382	5,806	13,647	5,552	1,372	90,338	37,005	
1. Higher managerial and professional occupations	42,021	26,200	160	517	808	751	421	144	10,084	2,936	
1.1 Large employers and higher managerial occupations	15,654	10,953	34	62	219	198	113	29	3,104	942	
1.2 Higher professional occupations	26,367	15,247	126	455	589	553	308	115	6,980	1,994	
2. Lower managerial and professional occupations	91,233	62,987	222	378	1,139	982	719	310	18,441	6,055	
3. Intermediate occupations	53,335	38,643	87	246	503	688	512	168	8,946	3,542	
4. Small employers and own account workers	28,627	19,458	70	509	542	1,137	590	75	4,361	1,885	
5. Lower supervisory and technical occupations	35,157	25,775	56	94	102	389	299	70	6,028	2,344	
6. Semi-routine occupations	61,341	44,618	127	219	343	1,254	557	130	9,861	4,232	
7. Routine occupations	48,165	34,492	51	150	103	1,004	566	67	7,973	3,759	
8. Never worked and long term unemployed	19,491	9,678	85	142	123	3,463	351	57	3,517	2,075	
L14.1 Never worked	14,300	6,571	66	127	91	3,139	300	25	2,365	1,616	
L14.2 Long term unemployed	5,191	3,107	19	15	32	324	51	32	1,152	459	
Not classified	141,109	100,128	540	1,127	2,143	3,979	1,537	351	21,127	10,177	
L15. Full-time students	54,294	29,203	418	854	1,014	2,750	935	172	14,902	4,046	
L17. Not classifiable for other reasons	86,815	70,925	122	273	1,129	1,229	602	179	6,225	6,131	

Table 6: Percentage of religious community members in different socio-economic groupsTable S157 ⁸¹Table population: All people aged 16 to 74

	ALL PEOPLE	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Religion		
								Any other religion	No religion stated	
	520,479	361,979	1,398	3,382	5,806	13,647	5,552	1,372	90,338	37,005
	42,021	7%	11%	15%	14%	6%	8%	10%	11%	8%
1. Higher managerial and professional occupations	15,654									
1.1 Large employers and higher managerial occupations	26,367									
1.2 Higher professional occupations	91,233	17%	16%	11%	20%	7%	13%	23%	20%	16%
2. Lower managerial and professional occupations	53,335	11%	6%	7%	9%	5%	9%	12%	10%	10%
3. Intermediate occupations	28,627	5%	5%	15%	9%	8%	11%	5%	5%	5%
4. Small employers and own account workers	35,157	7%	4%	3%	2%	3%	5%	5%	7%	6%
5. Lower supervisory and technical occupations	61,341	12%	9%	6%	6%	9%	10%	9%	11%	11%
6. Semi-routine occupations	48,165	10%	4%	4%	2%	7%	10%	5%	9%	10%
7. Routine occupations	19,491	3%	6%	4%	2%	25%	6%	4%	4%	6%
8. Never worked and long term unemployed										
L14.1 Never worked	14,300									
L14.2 Long term unemployed	5,191									
Not classified	141,109	28%	39%	33%	37%	29%	28%	26%	23%	28%
L15. Full-time students	54,294									
L17. Not classifiable for other reasons	86,815	100%	100%	100%	100%	100%	100%	100%	100%	100%

⁸¹ Leeds: The Leeds Initiative (2003)

Chart 1: Percentage of religious community members in different socio-economic groups



Appendix 3: Ethical Approval for the Research

Chairman Bill Kilgallon OBE
Chief Executive David Johnson

THE **LEEDS** TEACHING HOSPITALS

Local Research Ethics Committee

Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street, Leeds LS9 7TF
e-mail: comdhfo@stjames.leeds.ac.uk

10 July 2001

Enquiries to: Ann Prothero (Ethics Secretary)
Direct Line/Extension: 0113 (20) 65652

Ms G Mir
Research Officer
Research School of Medicine
Centre for Research in Primary Care
Hallas Wing
Nuffield Institute
71-75 Clarendon Road
Leeds
LS2 9PL

Dear Ms Mir

Project No 00/239: Communication, knowledge and chronic illness in the Pakistani community: natural histories of communication contexts, styles and outcomes and implications for the NHS

Thank you for your letter of 31 May concerning the approach to secondary care settings to help identify possible participants for the above study. I am happy to take Chairman's action and approve your proposals.

Thank you for attending our recent Committee meeting and giving us a presentation on your research and ethnographic methodology. We found it interesting and helpful.

Yours sincerely

Ann Prothero

Dr P R F Dear
Chairman
Leeds Health Authority / St James's and Seacroft University Hospitals
Clinical Research (Ethics) Committee

Local Research Ethics Committee

Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street, Leeds LS9 7TF
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23 January 2001

Enquiries to: Ann Prothero (Ethics Secretary)
Direct Line/Extension: 0113 (20) 65652

Professor W Ahmad
Centre for Research in Primary Care
Nuffield Institute
71-75 Clarendon Road
Leeds
LS2 9PL

Dear Professor Ahmad

Project No 00/239: Communication, knowledge and chronic illness in the Pakistani community: natural histories of communication contexts, styles and outcomes and implications for the NHS

Your study was considered at a recent meeting of the Ethics Committee and I am pleased to confirm that it was approved.

Members of the Committee found the methodology interesting and challenging and would like to invite you to give the Committee a short presentation on your research programme, and ethnographic methodology in particular, at one of our future meetings.

We will be having meetings on 3 April, 1 May, 5 June and 3 July at 4.30 pm at St James's University Hospital. If you would be willing to come along and if any of these dates is convenient, please let Ann Prothero, Secretary to the Committee, know at the above address.

We would be very interested in receiving a report of your findings at some future date.

Yours sincerely

Ann Prothero

Dr P R F Dear
Chairman

Leeds Health Authority / St James's and Seacroft University Hospitals
Clinical Research (Ethics) Committee

Appendix 4: Topic Guides

Key informants

Introduction: Information sheet.

Interviewees involvement in health/community issues related to Pakistani people

Experience of chronic illness (own; family/friends/community)

Communication

What do you think are the most important things to think about in terms of communication and Pakistani communities?

In your experience what factors affect the communication process between Pakistani patients and health professionals (eg deference, ability in English, cultural factors, prejudice, stage of illness, site of communication)

In your experience, how do Pakistani patients and their families deal with chronic illness?

e.g: express themselves, gain information, make decisions

What are the effects of the following on communication patterns:

- age
- gender
- class
- length of time in UK
- level of religious practice
- level of contact with British culture

eg do these things affect dominance in interactions/how information is interpreted/family roles/sources of knowledge/receptivity to persuasive messages

Do you think there are differences in communication with different professionals (eg nurses, GPs, consultants)?

What kinds of things do Pakistani patients need to communicate about in relation to their illness (eg practical issues, understanding of the condition, emotional difficulties)

Who they should be able to communicate with about these issues?

Do you think communication patterns change over the course of a person's illness?

What are the similarities/differences in the way the following people think about chronic illness:

- Patients
- Families
- Social networks

- Professionals?

What kinds of things enable/hinder effective communication?

How do you think communication with Pakistani patients can be improved? (eg in clinical settings/through community networks/through family networks). What do you think are the most effective methods?

Do you know of any health interventions based on increasing/improving communication with patients (eg counselling, liaison workers,) How effective are these for Pakistani patients?

Information

What kind of information is needed/wanted by Pakistani patients with chronic illness? Is this needed at certain times more than others?

How is this information acquired?

What benefits such information can provide?

Can you think of anything which might affect how information is processed?

Do patients/their families have changing information needs over time?

In your experience how do patients manage lay (non-medical) knowledge alongside 'official' information about illness

Are there others apart from patients who may need knowledge about their condition?

Why do they need it? How do they acquire it?

Do you think there are differences within the Pakistani community about the level of information required (what kinds of difference/causes of difference)?

Do you think there are any differences between Leeds and Bradford when it comes to communication and information? Is there any particular to this area that wouldn't be the same in the other?

Decision- making

How are decisions about health affected by families

social networks

beliefs

access to information

What other factors affect decision-making eg expediency/ effectiveness of treatment

Meaning attached to illness experience

Attitudes/autonomy/self-perception

Age, gender, class, length of residence in
Britain, religious practice, level of contact
with British culture

If not already mentioned

How does being Muslim affect patient's: relationship with health professionals

Sources of information

Decision-making

Anything else you want to add?

Thanks – (to community based contacts): do you mind if we keep in touch with you during the course of this research? (to make sure that people from the community stay involved in the process and have a say in how we carry it out)

Patient Interview 1 (June 2001)

Thank you for agreeing to be interviewed. We are trying to find out about how people with chronic illness gather information and build up their knowledge about their condition. We also want to know how the people they meet and know help them to do this.

This research will help us to recommend better ways of giving information to Pakistani patients. Your experience is very important to our study. We would like to speak to you now and then in six months and a year's time so that we can measure changes over this time. Whatever you say will be confidential and no names will be used in our final report.

Personal Details

I'd like to start by asking you some details about yourself

Can you tell me something about the area you live in ? (how long lived here, type of housing, neighbours, community organisations in the area)

Can you tell me about your family

Partner

Children

who lives at home

their ages/education/employment

Whereabouts do your other relatives live?

How often do you see them?

How easy is it for you to get out and about?

Do you have your own car?

Who are you close to?

How old are you?

Which country were you/your parents born in?

How long have you lived in the UK?

Do you work? (type of work, relationship with colleagues in/out of work)

Can you tell me something about your religious practice?

Do you go to any of the mosques?

Do you attend any religious gatherings?

How much does religion affect your daily life?

Diagnosis

What is the health of other people in your family like? (Other chronic conditions, how long ago diagnosed, treatment received)

What is the name of your condition? (diabetes/sugar, coronary heart disease/heart condition, blood pressure/hypertension, depression)

Do you suffer from any other conditions apart from this?

How did you find out you had [name of condition]?

When did you first think there might be a problem?

What did you do? (actively seek help/information, uncertainty about what to do)

Who did you tell? (whether discussed with others, why particular people chosen, their response)

What do you think caused this illness?

How long did you take before you went to the doctor?

What made you decide to go (discomfort, own worries, encouragement of others)

Did anyone go with you? (reasons why, why not, interpreter)

What did your doctor do when you went to see him/her (examination, referral, information, attitude)

Did you understand what was going on?

How long after you first went to the doctor did you find out you had [name of condition]?

What did you do when the doctor told you that you had this condition?

Did you ask questions? (what kind, why not?)

Who did you tell? (reasons why particular people chosen)

What was their reaction?

Was there anyone you did not tell? (reasons)

Have you seen anyone else apart from your GP about having [name of condition]?

Information

When a person is ill he/she may get advice and information from different people - health professionals, family/relatives, friends, community workers

What kind of information or advice have you been given?

about medicines (see further questions below)

diet (")

lifestyle (")

about services (")

benefits (")

other kinds of information (“)

For each of the above

Who gave you this information?

For non-family members/GP: How did you come into contact this person? (referral, recommendation, own initiative)

How was the information given to you (verbal/written/audiotape/videotaped)?

Where were you given the information? (surgery, hospital, home, community centre)

Has this information been helpful (understandable, accurate, sufficient, relevant to own lifestyle)

Have you acted on this information/advice? (reasons why/why not)

Who would you speak to if you wanted to know more?

Do you know anyone else with [name of condition]?

Has he/she given you any advice or information? (eg on diet, lifestyle, services)

Has it been useful?

Have you found information from anywhere else? (radio, TV, internet)

How did that happen?

How useful was the information?

How easy or difficult has it been to get the information you need?

Is there anything you feel you need more information about now?

What would you do if wanted to know something now?

How would you improve the way you have been given information about [name of condition]?

Do you think religious teachings can give you any useful information about your health?

Examples/reasons for opinion

Where would you get this kind of information from?

Communication

Obviously you have to talk about being ill to other people at times

How do you feel about talking about your illness?

with professionals

Family members

Friends/neighbours?)

Who do you talk to most about your health? eg which family members, which health professionals (reasons)

Who do you talk to least about your health? eg Relatives, friends, family members
(reasons)

Do you think that the way people behave or speak to you is affected by:

One at a time:

The language you speak?

The way you dress ?

Your gender?

Your level of education?

Your financial circumstances?

Your religion?

Your age?

[for each, draw out examples or reasons for point of view]

Do you ever feel like you should not talk openly about your health?

With professionals

With family members/relatives

With friends/neighbours

Why do you feel like that? (eg lack of time, worrying others, mistrust)

Would you like to be able to talk more openly sometimes? (reasons)

If yes What changes are needed that would help you to do this?

Do you feel that language is a problem? (eg access to interpreters, use of jargon)

If relevant who provides interpreting for you?

Why do/don't you use professional interpreters?

Are there some places where it is easier to talk about your illness?

Are there places where you find it more difficult to talk about your illness?

Are some things about illness that are easier or more difficult to talk about?

Who can you talk to about physical symptoms

feelings

worries

the future

family pressures?

Are there some times when it is easier or harder to talk? (Eg when you are in pain/When you are relaxed/Certain times of the day)

Family Influences

How involved is your family in the treatment you are getting?

Do they go to appointments with you (reasons)?

-
- Have they been told about the medicines/care you need?
 - Do they understand the condition/treatment?
 - How do you feel about the level of their involvement?
 - Do your family members make it easier or harder for you to get information?
 - Do they make sure you understand what is going on?
 - Do they allow you to ask questions or talk to professionals
 - Do they tell you about things that can help you?
 - Do they take you to people who can help you?
 - Have people in your family done things that help you manage your illness in daily life?
 - Help with treatment, diet, exercise, emotional support
 - Do you have disagreements with people in your family about how to manage your health? (examples, reasons)
 - How do you deal with disagreements?

Effect of /Meaning attached to Illness

Illness affects people in different ways and the way they think about it can be important in finding the right approach to treatment. I would like to ask how you think about your illness:

When you think about [name of condition] what kinds of things come into your mind? (eg weakness, a test, dependence,)

What effect do you think this condition has had on you? (your life)

Has it affected your relationship with other people? (family members, relatives, friends, neighbours)

Has it affected how you think about yourself? (confidence, body image, status, character)

Have you talked about these things with anyone?

Would it help you to be able to talk about these things?

Of all the people you know, who do you think best understands the effect of illness on your life?

Since you became ill has the way you talk or behave with other people changed? (examples, reasons for change)

Have you ever asked yourself why this illness has happened to you? ('Why me?')

What does your religion teach about health and illness?

Community Influences

There are many Pakistani people living in this area and I want to ask you about living in a community

Do you feel that you are part of the Pakistani community in your area?

Who do you meet on a regular basis? (relatives, neighbours, friends, groups)

Do you go to community events (melas, Eid parties, other events)

How do you find out about them?

Do you have much contact with people who are not Pakistani? (where, who?)

Are you part of any community organisations? (eg Montague Burton, Milun, Leeds Health Focus, Islamic Centre/ Bilal/Al Hassan mosque, other)

How often do you go? or Why don't you go?

How long have you been going?

How did you start going?

Do these places help you with your health in any way? (information, social contact)

Does it make a difference to you who is running a group? (background/ religion of organisers, place where group is held)

How important is the personality of the person running the group? (eg friendliness, good manners)

In your experience does being ill make a difference to how other people in the community treat you? (behaviour, talk, positive and negative aspects of change)

Decision Making

People with long term illness have to make decisions about many things eg which medicines to take, whose advice to follow, whether or not to use services

What kind of treatment are you taking for [name of condition]

Are there any reasons that would make you stop taking some medicines?

Who would you speak to if you had any worries about your treatment?

Do you use any alternative treatments:

Hakim

Massage

Homeopathy

Chinese medicine

What made you decide to use/not use them?

What do you expect from these kinds of treatment?

Who told you / Where would you find out about these treatments?

Have Pakistani people used these treatments in the past or are they new kinds of cures?

If using Does your doctor know you are using these other treatments?

If told What was his/her reaction

If not told why have you not told him/her?

Do you ever get different advice from different people? (examples)

Whose advice do you follow (reasons)

Who is involved in making decisions that affect you?

About medicines) self alone, professionals, family members, others

About diet)

About lifestyle)

About services)

How much control do you feel you have over decisions about your health or treatment?

Management of Illness in Daily Life

How do you feel you cope with your illness in daily life? (periods of coping/not coping)

What things help you manage? (eg treatment, changes to lifestyle, family support, prayer)

What do you find most difficult?

Are you satisfied with the level of support provided by

Doctors/other health practitioners

Your family

Relatives

Your community

What do you do when you feel it is difficult to manage?

How do you deal with your worries?

What kinds of services would make it easier for you to cope?

Have you ever tried to find out whether these kinds of services are available?

if not: reasons

if yes: what did you do?

did you have any support with this?

what did you find out?

What advice would you give to other people who have just been told they have [name of condition]?

Is there anything else you would like to add?

Thank you very much for giving your time and telling us about your experiences. If there is anything you would like help with relating to your health eg accompanying you to appointments, I am happy for you to contact me and I will do what I can. I will contact you in about five months time about another interview but, if you do not mind, I may give you a ring now and then to see how you are. [Give own card with telephone number and name].

Patient Interview 2 (January 2002)

These questions have been developed from the interviews we carried out in summer last year. We would like to ask you about how things have changed since that time and also other areas that are useful for our research.

Changes since last interview

Since I interviewed you six months ago what would you say has changed?

- General perceptions of own health
- Explore perceptions of health professionals, treatment
- Changes in sources of information. Reasons why other sources sought/not sought
- Any changes/experimentation in treatment, activities, beliefs

Relationships with health professionals

- Last time I spoke to you, you felt that your GP/other health professionals were [describe according to transcript]. Do you still feel like that? Can you give me an example of something that health professionals do that increases/decreases your confidence in them?
- [for people who have not complained about relationship with HPs]: 'How does your GP/the hospital respond when you complain of pain or discomfort/need help with any problem?'
- What do you think is a reasonable time period for
 - minor
 - major
 - recurrent problems to be dealt with effectively?
- Some people have said they are afraid of upsetting their doctor. Is there anything you would not like your doctor to know about the way you are managing your illness?
- Would you have any worries about complaining to your GP or the hospital if you were not happy with your treatment?
- [JK/QI/AB/NL]: 'Some people worry about making a complaint/putting pressure on the [health professional] but you have still gone ahead – what made you decide to do that?'

Relationships with family members/community

When we spoke to people last time some were worried about becoming a burden on others/being a nuisance because of health needs. They mentioned the difficulty of asking for help even when family members willing

– *for example because they can see others are busy* Way of life in UK makes support from family more difficult. Different attitudes in this country to caring, to talking about their problems especially in relation to family illness also can affect a person's ability to reciprocate visiting/contributing to family roles, status may drop as a result. I would like to ask your views about these kinds of things.

'Do you think family relationships are different in the UK than in Pakistan? Are people here more worried about depending on their families than people living in Pakistan?' (has this been considered a right rather than a burden in the past?)

Do you think asking for help can make a difference to your relationship with people?
(positive and negative changes)

Explore feelings about being in need of help from other people (relate to own history/changing perception of self)

Is it easier to ask for help when you have a certain illness eg a heart condition rather than diabetes?

Immediate family and 'biraderi' (extended kin network) main source of social contact for most patients.

- Within your biraderi, how many people are knowledgeable about health? Where do they get this knowledge from? How do they use this knowledge within the biraderi. Is there anyone in particular you would speak to if you wanted to talk about [condition]?

Negative cases [OB, UC, JK]:

- Explore how lack of family contact makes a difference to the way they deal with their condition. How would they make use of family in relation to their health if this were possible?

Some people told us they didn't feel it was right to ask for help outside their own family. What do you think about this?

- Explore consequences of receiving such help eg 'What do you think people outside the family would think or do if you asked for help from them?'

Negative cases (those using local agencies or neighbours/friends for advocacy/support)

- Could you get this kind of help from anyone within your family? Who do you prefer to give you this kind of help – family or [others]? Explore reasons.
- What is the difference between getting help from paid professionals and from relatives?
- What is the difference between getting help from relatives and from friends or neighbours?

Health beliefs

Some people said they felt that worries were a reason why people became ill

- Do you think this is true? [If yes] What kinds of worries make people ill? [If no] What do you think is the main cause of illness amongst Pakistani people?
- Do you think English people think this way too? Why (not)?

Exercise and diet were also mentioned as important ways of improving health

- Last time we spoke you said that [re diet]. Has anything changed since then?
- Explore any changes in exercise activity and attitudes to exercise

People also mentioned the importance of routines in keeping healthy, eating/taking medicine/checkups / sleeping/ religious activities- following an organised and predictable pattern. Linked to being able to rely on others

- How important do you think it is for your health to be organised and have a regular routine, to know what is going to happen at what time?
- What would help you to stick to a routine? What would stop you from being able to follow a routine?
- Does anyone else need to be involved to make sure you can be organised in this way?

People also said that differences between the UK and Pakistan are a reason for many Pakistani people having poor health: increased risk of illness because of cold climate – less perspiration which is good for health. Lifestyle in UK more sedentary, less physical work. Better health reported in Pakistan.

- Do you agree with that view?
- Explore differences in lifestyle, different position in society, effect on health.

Treatment

- Last time you said that your views on your medicine were Explore whether feelings about medicine have changed and reasons for current attitude
- Since I last spoke to you have you used or come across any alternative medicines for [condition]? If yes - What made you decide to use/ not use them?

Personal experience an important factor in decision making - combined with knowledge from various sources (clinical/family/community) see 'Information' below.

Patient as expert on own health (PH, Su B, IJ)

Specific understandings of how the body works eg healthy heart cleans the blood and stops buildup of cataract in the body (NE); sugar in the blood is more severe than sugar in the urine which can be cured (TC).

- Explore origin of these health beliefs and influence on how illness is seen/managed

Religion

- Effect of current events in Afghanistan and Pakistan across cases. Whether felt to affect general health. Perception of own position in UK society.
- Do you think these things have had an effect on your relationships with health professionals?
- Last time we spoke you said that religion was Do you think your views have changed in any way since then?
- How did you manage in Ramadan? Did you fast? [Advice taken from doctor/relatives/how decision made/feelings about fasting or not fasting]
- Have you been listening to Radio Ramadan? What do you think about it? What kinds of things do you like/dislike about it? Have you heard any programmes that relate to health?

Language and Communication

We found last time that people felt you should suit the way you speak to where you are and who you are speaking to. For example many people spoke to me in Urdu even though I and they were usually Punjabi speakers.

- Do you think that some languages have less status than others?
- Where would you expect to hear or use Mirpuri/Punjabi/Urdu/English?
- What do you learn about a person from the kind of language he/she uses?

Some people felt that it was not good to ask too many questions and they did not always want to know a lot about their illness

- What do you think about this point of view?
- Do you think it is sometimes unhelpful to have a lot of information?
- Are there any disadvantages to knowing a lot about your illness?

Other

We would like to ask some other questions that we think affect how people gather information and make decisions about their health

- Explore employment/last job,
- level of formal education,
- length of time in UK

Patient Interview 3 (June 2002)

Before the interview – mark down all places previously mentioned on map and list at side.

Write interviewees name at corner of map. Make a note of the main issues seen as problems and the main people/sources of influence mentioned in previous interviews.

Thank you for agreeing to this third interview. We really appreciate the time you have given to this research. We hope that it will lead to improvements in the way health services give information and healthcare to people within the Pakistani community. This interview will both questions and activities to talk about things that are important to your health. If you have no objection I will record the interview so that I don't miss anything you say.

- **Questions about continuity and change**

In the last six months or so (since I last interviewed you) can you tell me if there has been any change in

Your medication?

Where you get information about your health from? (any new sources of info/advice?)

How much you know about your condition?

The way that you manage your health

Your relationships with doctors or healthcare staff

Family members

People or groups in the community

What do you expect to happen in terms of your health in the next six months (better/worse/same)? Reasons for point of view?

I would like to use a different way of asking questions now, using some activities we have developed to help discussion. First can I show you a map of the local area?

Point out house, GP, main roads and local shops [organisations already mentioned in previous interviews should have already been marked on]. Go through mapping activity according to questions on map. Where we have made referrals also ask whether referral made any difference to the problem concerned.

Thank you. Next I would like to show you some cards that mention problems that people often have when trying to manage their health. The cards use English, Urdu and pictures so that everyone can understand them. I would like to ask you to pick out the cards which show things that cause most problems for you in looking after your health.

Lay out cards one at a time saying the word on each as you put them down.

- Which three things cause you most difficulty in managing your health?
- Ask about nature of problem and possible solutions (who could help/where/when should help be offered?)

Have you ever heard of XX? (mention organisations that could help but which not mentioned on map

I would like to use another set of cards to ask you about who influences your decisions about your health? Can you tell me which of these has the most influence on your decisions

Go through cards one at a time.

Identify main decision maker and place in centre

For each of the other cards place at a distance from centre depending on level of influence

Discuss nature of influence of two closest circles

Discuss reasons for low influence of two farthest circles

- Is the influence any different for
 - diet?
 - Medication?
 - Exercise?
 - General daily routine?
 -

We would like to speak to the two people who influence you most so that we get a full picture of your healthcare and any problems that they have noticed. Would you give permission for us to interview X and X? (family/friend/professional mentioned as most influential)*

Professional people need to have your permission in writing. Can I ask you to sign this consent form so that we can write and ask to speak to them?

How should I contact your family member/ friend?

- Thank you that has been very helpful. How do you feel about the way we interviewed you today? Did you prefer it to the kinds of questions we asked before or not?

if necessary explain further *We will ask them about what they feel helps you manage your condition and any support that would help you further.

Thank you again for your support with this research. We will send you a summary of our report once this is finished. What would be the best way to do this? (written in English/ Urdu or cassette version?).

Information about dissemination activities

Offer suggestions/follow up about organisations that might help with identified problems if not already.

Carer Interviews⁸²

Thank you for giving some of your time for this research. We hope it will lead to improvements in the way Pakistani patients receive healthcare. We would like to talk about your views on the healthcare X has received and how he/she has built up their knowledge about [condition]

I would like to start by asking you how much has changed over the past year or so since X was first diagnosed with [condition]

How much did you know about [condition] before X became ill? What about now? Do you think you know enough?

How much did X know about [condition] before s/he was told s/he had it?

- Causes/treatment/future development of the illness

What about now? Do you think s/he knows enough?

Before X was told s/he had [condition] who did s/he ask for information and advice about health? What about now? [reasons for change if any]

Since being told s/he has [condition] would you say there has been any change in X's relationship or attitude towards

- family members
- people in the biraderi
- health professionals – dr/others
- friends/people in the community
- religion

Generally how do you feel X manages his/her health?

What affect has his/her illness had on you?

Seht day
saholta
wich
behtri

Badalya

*Jitna
sara
jandayo
batera
hay?*

*Bemar
hon tu
pehla*

*Rawiya
ya
talaqat*

*Dr/nur
se
wagher
a*

*Apna
dekh
baal
kistara
kar
lenden?*

⁸² Words transliterated in the text box on this topic guide were agreed between myself and my male colleague to achieve some standardisation in the way we translated questions into Punjabi/Mirpuri dialect

How are you coping? Do you feel you would like some support for yourself?

From whom?

Now I would like to ask you some questions about the support X receives in managing her health

What advice has X been given about medicine? From whom?

How much does he/she follow the advice (reasons)

Same questions for diet

Has he/she been given any other advice? If so same questions

Have you met X's doctor(s)? What do you think of them?

What kind of relationship does X have with his/her doctor(s)? what are the reasons that this relationship is good/bad.

How much have you been involved in discussions with the doctor/ other healthcare staff?

Can you think of any way in which the way doctors look after X could be improved?

Who else is important in looking after X?

- Other health professionals (eg nurse, dietitian, physiotherapist etc)
- What do they do that is helpful to X? what could be improved?
- family members (self, anyone else). What do you/others do that is helpful to X. What could be improved?
- other professionals (eg community based workers/social worker).

Which community based groups do you know of in the area that X could use? Do you think X should use community groups? Why are these useful/not helpful?

How much notice does X take of advice or information from

- family members
- people in the biraderi

Dr behtar
dekh baal
kistara kar
sakden?
Awr kon
zuroori
madad
karda?

Keh
karden?
Is madad
wich
behtar
keh ho
sakda

- health professionals – dr/others
- friends/people in the community
- religion

Are there any areas where you feel X's healthcare could be improved?

How could this be achieved?

Who should be responsible for this?

Is there anything else you would like to add?

We will be sending out a written or taped report about the research – which type of report would you prefer?

Thank you very much for your time.

Information about dissemination activities

Professional Interviews

Thank you for giving some of your time for this research. We hope it will lead to improvements for patients and professionals in the way healthcare is delivered. We would like to talk about your views on the healthcare X has received and how he/she has built up their knowledge about his/her condition.

Knowledge about health and illness

Generally how do you feel X manages his/her health?

How much do you think X knows about his/her condition?

(causes/treatment/future development of the illness)

Has his/her knowledge changed since he/she was first diagnosed?

Reasons for any change.

Do you think s/he knows enough?

Apart from yourself where could X find information and advice about his/her health?

What kind of relationship do you feel you have with X? (Reasons for good/bad/indifferent relationship)

Since being told s/he has [condition] are you aware of any change in X's relationship or attitude towards you?

Treatment and healthcare

What advice have you given X in terms of treatment? (medicine/diet/exercise) How much does he/she follow the advice? (reasons for adherence/non-adherence. Own response to non-adherence if relevant).

Has he/she been given any other advice/treatment? (eg hospital/alternative treatment). If so how do you feel about this? Are there any areas which conflict with your advice/treatment? How do you deal with this?

How much liaison is there between yourself and others involved in X's treatment?

Who else is important in looking after X ?

- Other health professionals (eg nurse, dietitian, physiotherapist etc) What do they do that is helpful to X? what could be improved?
- family members. What do they do that is helpful? What could be improved?
- other professionals (eg community based workers/social worker).

Use of resources

Are you aware of any community based groups in the area that X could use? Do you think X should use these groups? Why are these useful/not helpful?

How much notice does X take of advice or information from

- health professionals – dr/others
- family members
- friends/people in the community

Does X's religion have an influence on the way he/she managed his/her health?

Are there any areas where you feel X's healthcare could be improved?

How could this be achieved?

Who should be responsible for this?

Do you feel X could improve the way he/she manages his/her own health? In what way?

Is there anything else you would like to add?

We will be sending out a written summary of the findings from the research

Thank you very much for your time.

Information about dissemination activities

Appendix 5: Participatory research methods

Community mapping: map of fieldwork area (A3 sheet)

Interviewees home/GP surgery/ main roads/to be marked on map before interview

- **Identify other GPs surgeries on the map**
- **Known organisations used by the Pakistani community**
- **Comment on quality of service (very good, good, OK, could be improved, poor) Where referred by us – did it make a difference?**
- **Comment on ease of access**
- **Places where there is a chance to mix with non-Pakistani communities – whether used and reasons**
- **Identify other places visited most often and why (eg where carers/friends live, social/ shopping sites).**

Which of these places are most important to you in keeping yourself healthy?

Prioritising problems – cards to include Urdu translation and relevant picture

- Order cards into those which never/sometimes/often cause problems in managing health
- Place 'often' cards in priority order (what causes most problems in managing condition). Use 'sometimes' if necessary
- For first three cards ask about nature of problem and possible solutions (who could help/where/when should help be offered?)
- Discuss any inconsistencies with problems highlighted in previous interviews and explore reasons for change.

Cards for following:

GP
 Family
 Knowledge/skills Diet
 Treatment
 Physical or mental discomfort
 Hospital
 Being taken seriously
 Where you live
 Appointments
 Money
 Not enough support
 Work
 Confidence
 Language
 Exercise
 Transport
 Housing
 Paperwork
 Time
 Attitudes

Treatment

علاج



Transport

سفر کا ذریعہ



Influences on decision-making

- Identify the main decision maker in choices about health and place in centre
- Place each circle at a distance from main decision maker, depending on level of influence
- Discuss nature of influence of two closest circles and reasons for low influence of 2 farthest
- Place in priority order for who influences most on diet/medication/exercise/daily routine
- Ask for permission to speak to most influential professional/family member or friend.
- Give consent form for professional interview

Cards for following:

Self

GP

Hospital doctor

Family member/ relative

Community group

Books/ written material

Leaflets from hospital

Religion

Other professional person

Friend/ work colleagues

Media (TV/ radio)

