



Long-term ill-health and livelihoods
among Pakistanis in the UK: class,
gender and household economies

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Statement of own work

Declaration by candidate

I have read and understood the London School of Hygiene and Tropical Medicine's definition of plagiarism and cheating, as given in the Research Degrees Handbook. I declare that this thesis is my own work, and that I have acknowledged all results and quotations from the published and unpublished work of other people.

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Abstract

A growing body of literature on health and social inequalities has identified Pakistanis as having a particularly heavy and premature burden of long-term ill-health compared with people from other ethnic backgrounds, and long-term sick Pakistanis are also a sub-population in the UK with disproportionately high rates of unemployment and inactivity. In this thesis, I argue that there is a need to turn fresh attention to the practical and material consequences of ill-health, and to the impact of ill-health on livelihoods. I make a case for shifting the focus of medical sociology and medical anthropology away from the subjective, psychological processes of coming to terms with, coping with and managing a long-term health condition, and onto the realm of overt behaviour and the everyday consequences of living with ill-health in specific historical contexts. I also make a case for examining how the experience and consequences of long-term ill-health are embedded in the local worlds of family, household and community, and how these are inflected by power relations.

The thesis broadly documents the process of impoverishment engendered by ill-health, stressing how the economic impact of long-term ill-health is embedded in particular production and welfare regimes and differentiated by generation, class, education and gender among Pakistanis. Far from being a uniformly deprived and disadvantaged group located at the bottom of British society, I examine the significance of class relations and social mobility among Pakistanis, and show how long-term ill-health contributes to increasing economic polarisation within the community. Within certain material and cultural constraints, individuals and households also resisted the potentially ruinous consequences of long-term ill-health and impoverishment, and strived to maintain social status and membership in a moral community by engaging in strategic action via their interconnected means of production, consumption and reproduction, within a specific local regime of value.

The thesis employs a mixed-methods approach combining statistical analysis of the Labour Force Survey with ethnographic material from East London. It is located analytically in Bourdieu's 'theory of practice' (Bourdieu 1977), which offers a way to formulate the interface between structure and agency, and material and cultural factors as interweaving influences on the predicaments of long-term sick Pakistanis.

Dedication

This thesis is dedicated to my family members, near and far, and especially to Gordon White, who I would have loved to be able to turn to over the course of this research.

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Last but not least, my deepest gratitude goes to all the informants for so generously giving their time and sharing their experiences. This research would never have been possible without them, and I hope I have done justice to what they told me. To bring home the gravity of what follows in the pages of this thesis, I would like to remember that five of the long-term sick individuals have now died since the interviews took place. This research was not able to help them directly, but I hope that its findings can be of use to other people suffering severe ill-health.

Foreword

This study was nested within a wider project on long-term ill-health, ethnicity and poverty, which was supported by the NGO Social Action for Health and funded by the Joseph Rowntree Foundation (JRF). The JRF project compared the relationships between long-term ill-health and poverty between four ethnic groups: White English, Pakistani, Bangladeshi and Black African. The findings of the project are detailed in the report led by Salway and Platt (2007). This study contributed to the JRF project but is an independent piece of work, as it was intended to focus exclusively on Pakistanis; how their experiences of long-term ill-health were shaped by material and cultural contexts; and the impact of ill-health on the household as a site of production, consumption and reproduction. In addition to the quantitative analysis and twenty in-depth interviews with Pakistanis that contributed to the JRF project, this thesis is the product of substantial additional data collection and analysis; a prolonged ethnographic study, which provided insights into people's longitudinal trajectories with ill-health; participant-observation in the sending areas of Pakistan; an extra thirty in-depth interviews, pursuing fresh lines of questioning; and contextualisation within the historical setting of East London.

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Chapter 1: Background and theoretical orientations

kabhi khushi kabhi gham

sometimes sorrow, sometimes joy – Urdu saying

1.1. Introduction

Pakistanis, compared with other major ethnic groups in the UK, suffer from an untimely and disproportionately heavy burden of long-term ill-health. They are likely to become ill prematurely in their 30s and 40s (Nazroo 1997). As long-term ill-health is currently one of the most important underlying causes of impoverishment in the UK, this thesis responds to the clear need for a better understanding of the experience and consequences of long-term ill-health among Pakistanis, particularly as the population of Pakistanis in the UK – as well as their dependants in Pakistan – continue to age (Rendall and Ball 2004).

Perspectives on long-term ill-health in medical sociology and medical anthropology have tended to focus on the subjective, psychological processes of coming to terms with, coping with and managing a long-term health condition. However, recently the case has been made for re-focusing on the realm of overt behaviours and interactions, and on the practical, everyday consequences of living with ill-health in specific historical, political and cultural contexts (Silverman 1998; Campbell 2000; Bury 2001). Sociological approaches to ill-health based on the individual ‘disease course’ and ‘sickness career’ have been challenged to take greater consideration of how experience is shaped by social structural and cultural conditions, and in particular, how it is embedded in the realms of family, household and community (Charmaz 2000). As part of this broad critique, there have been calls for more research on the links between the experience of long-term ill-health and ethnicity, as well as other forms of collective identities. Hicks and Lam, for instance, argue that research on ethnic minority groups “enables the cultural biases of Western-based theories of the [individual disease course] to be thrown into relief and made more apparent” (Hicks and Lam 1999) (p.416).

However, beyond the socio-cultural nuances that may be revealed by research on the experiences of long-term ill-health among groups like Pakistanis, long-term ill-health also has wide-reaching *material* consequences – which are more extreme, and a more pressing part of the experience of ill-health for groups that are marginalised like many ethnic minorities. Among the ethnic groups

in the UK, Pakistani men and women above age 25 have the highest rates of economic inactivity due to permanent sickness and disability (Szczepura, Gumber et al. 2004; Simpson, Purdam et al. 2006). In a review of the field to date, Charmaz shows that studies of long-term ill-health have largely left out those people who are “marginalised and difficult to trace – those who are isolated and impoverished... What happens when these individuals lose their livelihoods in addition to their health?” (Charmaz 2000) (p.290). Health economists have also concluded that more research needs to be done on the household costs of ill-health, household responses and their implications for poverty (Russell 2004). As Kleinman surmises, an interdisciplinary approach is required: “illness [can be] the precipitant of end-state immiseration. This is a powerful social consequence of illness that deserves far more attention in medical anthropology” (Kleinman, Wang et al. 1995) (p.1326).

This thesis therefore examines the experience and consequences of long-term ill-health among Pakistanis in the UK, giving particular attention to the practical and material consequences, and to the impact of ill-health on livelihoods. I analyse how individual biographies are shaped by historical, political and cultural contexts, and consider the implications of Pakistani ethnicity for the fortunes of the long-term sick.

As background to the study, this chapter sets out what is already known about the social realities of long-term ill-health among Pakistanis in the UK, introduces the research questions of the study and summarizes its main theoretical orientations and claims.

1.2. Long-term ill-health among Pakistanis in the UK

1.2.1. Defining long-term ill-health

Long-term ill-health is defined as: “health problems that require ongoing management over a period of years or decades” (WHO 2002) (p.3). It comprises a disparate set of conditions. The majority are non-infectious conditions such as heart disease, diabetes, arthritis, cancer, asthma and mental illness. However, some infectious diseases, like tuberculosis and HIV, can now also become long-term conditions. Long-term ill-health is inherently intertwined with the issue of disability. It is the underlying cause of two thirds of the disability in contemporary Britain, and disabilities can have similar disruptive consequences for personal biography, lifestyles and identities (Ahmad 2000). However, stable disabilities entail a somewhat different set of problems

from long-term ill-health. Long-term ill-health involves periods of nausea, fatigue and pain as well as the loss of functional ability, and symptoms are often episodic or progressive. It has been argued that the experience of long-term ill-health can be less easily integrated into a social model of disability because of the greater intrusion of medicine in controlling symptoms, and the greater role of individual management. With its focus on the oppressive practices which constrain the chances of disabled people to participate in society – what Pinder calls the ‘barriers and facilitators’ approach – the social model of disability provides only a limited understanding of the complex, multi-layered experiences of individuals who are living with impairment. Long-term sick people find it hard to apprehend their difficulties merely as the product of a disabling society, and negotiate an ambiguous terrain between being ‘sick-but-fit’ and ‘fit-but-sick’ (Pinder 1995; 1996).

1.2.2. Ethnic inequalities in health

Pakistanis in the UK are generally found to have a heavier burden of long-term ill-health than their counterparts from other ethnic groups, even compared to other South Asians (Bhopal, Phillimore et al. 1991). The Fourth National Survey of Ethnic Minorities in 1994 found that Pakistani adults, like Bangladeshis, were 40% more likely to report limiting long-term ill-health than White British people or people with Indian or East African Asian origins (Nazroo 1997). The Health Survey for England’s ethnic minority boosts in 1999 and 2004 showed that these differentials have persisted over the last decade, and for women, even deteriorated (Sproston and Mindell 2006). Worryingly, the ethnic differentials seem to have worsened in the second generation compared to first-generation migrants (Harding and Balarajan 2000). The ethnic differences in long-term ill-health increase progressively with age, particularly above age 30, and are greatest among elderly people (Evandrou 2000; Nazroo 2006).

As for the general population, the main types of long-term ill-health affecting people of South Asian origin are musculoskeletal conditions, endocrine and metabolic conditions, disorders of the heart and circulatory system and respiratory disease (Sproston and Mindell 2006). The risk of doctor-diagnosed diabetes is five times as high for Pakistani women as for the general population, and three times as high for Pakistani men (Chaturvedi 2003; Sproston and Mindell 2006). The risk of cardio-vascular disease is 50% higher for Pakistanis and Bangladeshis than for the general population (Chaturvedi 2003). Besides these differences in the overall prevalence of ill-health,

there are also ethnic differences in age of onset, clinical severity and the extent of comorbidity with other health conditions (Greenhalgh 1997).

The reasons for the heavy burden of long-term ill-health among Pakistanis in the UK are multi-factorial. Most of the excess ill-health among Pakistanis is explicable in terms of their disadvantaged socio-economic position compared with other ethnic groups (Nazroo 1997; 1998). However, ethnic inequalities in health cannot be understood merely in terms of the distribution of social disadvantage between groups. First, as Smaje points out, this logic desocialises and dehistoricises the processes by which material factors come to differentially affect the health of ethnic groups, and elides important questions about the ways in which socio-economic status is produced in different ethnic groups. To understand the production and reproduction of the social structure, the patterns of inclusion and exclusion that flow from ethnic identity must be taken into account (Smaje 1995; 1996; 1997). Second, the interplay of factors affecting ethnic inequalities in health is complex, including migration and geographic processes, racism and discrimination, culture, lifestyles and biological susceptibility in addition to socio-economic factors (Ahmad 1995; Davey Smith, Chaturvedi et al. 2000; Fenton and Charsley 2000; Fenton and Karlsen 2002; Karlsen and Nazroo 2002; 2002b; Bartley 2004; Ahmad and Bradby 2007; Bhopal 2007). The research on racial equity in healthcare delivery and take-up has presented a complex picture. Survey data suggests higher than average use of primary care by certain minority ethnic groups, although not relative to need; lower than average use of secondary care; and ethnic differences in the quality of experience (Aspinall and Jacobson 2004; Commission for Health Improvement 2004; London Health Observatory 2006). Ethnic differences in the treatment and management of severe mental health conditions are extreme, although this appears not to be the case for community mental health services (Fearon, Kirkbride et al. 2006; Raleigh, Irons et al. 2007).

1.2.3. Economic consequences of long-term ill-health

“All that it takes to push families off their thin perch is a serious illness” (Kleinman, Wang et al. 1995) (p.1326). Long-term ill-health can be a powerful source of downward mobility; it can be a cause of impoverishment as well as a barrier to movement out of poverty (Kemp, Bradshaw et al. 2004). The relationship between long-term ill-health and poverty is dynamic. Longitudinal analysis of the British Household Panel Survey indicates that long-term ill-health is one of the most important causes of poverty-related mobility trajectories. Eight percent of cases where an individual moves into poverty are triggered by a rise in the number of household members with

limiting long-term ill-health, compared with 16% by a rise in the number with poor mental health (Jenkins and Rigg 2001). Child poverty, furthermore, is particularly affected by adult ill-health or disability (Adelman, Middleton et al. 2003).

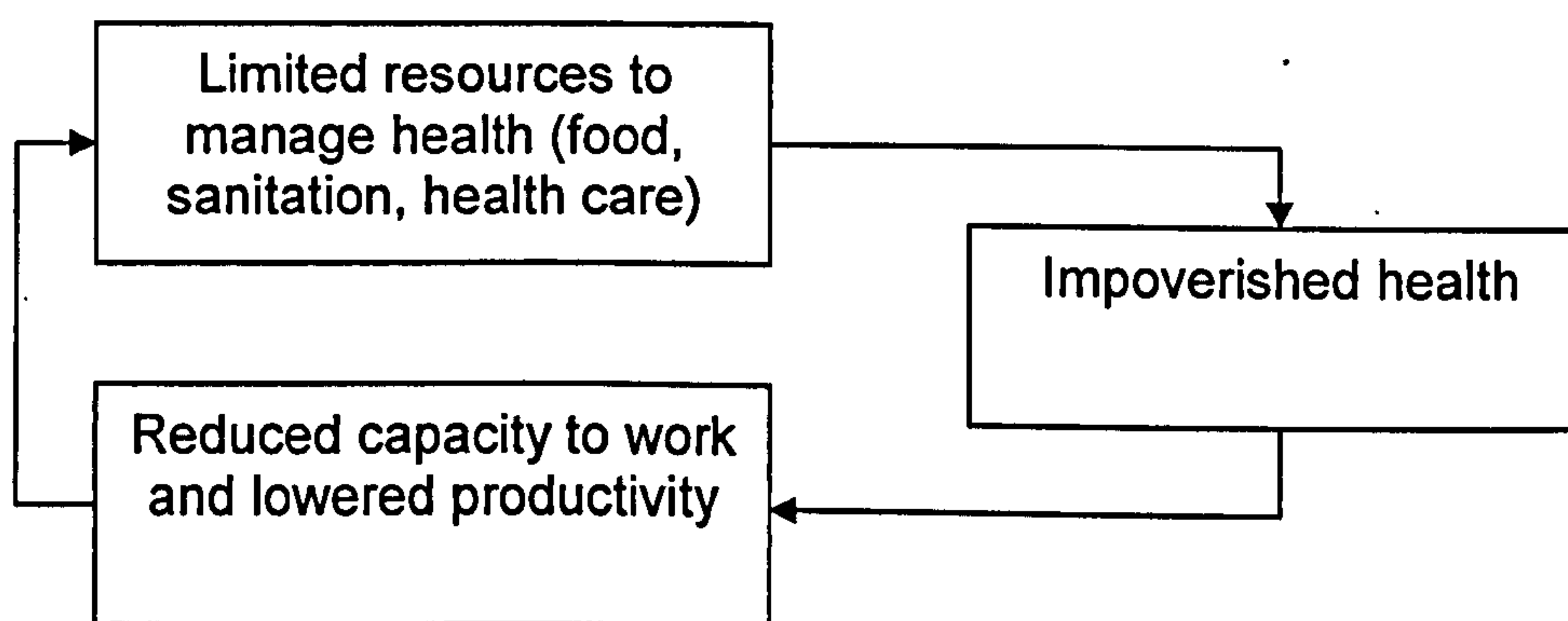
The WHO has modelled the process of impoverishment engendered by ill-health as a 'vicious cycle' (WHO 2002). First, poor people are at greater risk of ill-health to begin with. Second, long-term ill-health can impoverish people due to a combination of factors:

- I. **direct costs** concerned with increased expenditure – long-term ill-health creates extra needs, such as special diets and clothing, heating, wheelchairs and other aids, paying for healthcare or care services; caregivers may also have to spend more on transport, phone bills, adapting their homes, increased wear and tear, repair and maintenance costs, paying for care for other dependents, or due to constraints on their time (e.g. being forced to buy convenience foods or take taxis) (Locker 1983; Parker 1993).
- II. **indirect costs** concerned with incapacity from work, reduced productivity, absenteeism and early retirement – long-term ill-health can make work problematic, as it can restrict activities, the number of hours that can be worked, and the environments that can be worked in. Long-term sick and disabled people face multiple dimensions of disadvantage in employment, including lower average hourly earnings than their non-disabled counterparts (Burchardt 2000) and poorer job security (Bartley and Owen 1996; Burchardt 2000b; Jenkins and Rigg 2001). Unlike other types of economic shock, ill-health in one person also influences the economic activity of other household members, particularly caregivers, making them likely to cut down hours, miss days of work or leave work altogether (Charlton, Wallace et al. 1994; Smith and Twomey 2002; Henz 2004).
- III. **social costs** – social participation may be negatively affected by long-term ill-health, partly because of functional limitations and partly because of stigma and relationships becoming socially difficult (Ong, Jordan et al. 1999). Lack of social participation may restrict the household's access to networks, which are one of the most important resources mobilised in response to ill-health, and therefore exaggerate long-term problems (Whelan 1993).

Third, returning to the WHO framework, poverty can in turn make it difficult to access inputs to health, creating a downward spiral that affects not only the sick person but also their family or household (WHO 2002). The downward trajectory is likely to be repeated in the next generation, as parental ill-health is associated with poor schooling outcomes. Indeed, 20% of young carers in

the UK regularly miss school or suffer educational difficulties due to their caring responsibilities, and a disproportionate number leave school with low grades or no qualifications (Howard 2001; The Education Network 2005). These relationships are shown in Figure 1.1. The scenario of ill-health related impoverishment is most likely in countries that have failed to implement effective social safety nets. However, as McKee points out, “fuelled by the process of globalization, many countries have adopted increasingly deregulated employment regimes and have weakened existing safety nets so that the scope for ill-health... to impoverish families has been increased greatly” (McKee 2002) (p.55).

Figure 1.1: The impact of long-term ill-health on the poor: a vicious cycle



Source: WHO (2002) (p.12).

The economic impact of long-term ill-health is differentiated by type, severity and duration of the health condition. However, there is no point of severity at which there is a step-change in employment chances, and people who might be considered to have relatively minor forms of incapacity nonetheless face reduced employment chances (Berthoud 2006). In the UK, the greatest economic impact has been identified among people suffering from intermittent health conditions, whose variability may disrupt working life unpredictably and result in health-related benefits being disallowed (Bacon 2002). Children in households with adults with intermittent illness are the most likely to be in poverty (Adelman, Middleton et al. 2003).

1.2.4. Ethnic inequalities in the economic consequences of ill-health

The empirical literature suggests that the economic impact of long-term ill-health among Pakistanis, as for some other ethnic minority groups in the UK, may be particularly severe. Ethnic minority disabled people have lower economic activity rates than White disabled people, and are

more likely to be unemployed (Smith and Twomey 2002). Among all the ethnic groups, Pakistani men and women aged 25 and over have the highest rates of economic inactivity due to permanent sickness and disability (Szczepura, Gumber et al. 2004). The excess sickness-related inactivity has increased more for Pakistanis during the 1990s than for the other ethnic groups; and it is not localised to the economically declining areas of Wales, the North East and the North West, as found in other ethnic groups (Simpson, Purdam et al. 2006). Among carers, studies have shown that ethnic minority carers are more likely to be living in poverty than their White British counterparts (Young, Grundy et al. 2006).

Research from Germany and the USA also indicates that the *relative impact* of ill-health on employment may be greater for people from ethnic minority groups than for the ethnic majority (Arrow 1996; McDonough and Amick 2001; Bound, Waidmann et al. 2003). In the UK, the few studies that have considered this question have identified little difference in the effects of ill-health on labour market outcomes across ethnic groups (Berthoud 2003; Berthoud and Blekesaune 2006; Clark and Drinkwater 2007). However, there is a need to examine these relationships in more detail, given the evidence for differentials in the employment consequences of ill-health according to factors that vary between ethnic groups:

- I. **occupational class:** long-term sick people with working-class occupations are more likely to end up out of employment than professionals (Blank and Diderichsen 1996; Bartley and Plewis 1997; van de Mheen, Stronks et al. 1999; Burstrom, Whitehead et al. 2000; Lindholm, Burstrom et al. 2001; McDonough and Amick 2001; Lindholm, Burstrom et al. 2002; Burstrom, Holland et al. 2003);
- II. **education:** long-term sick people with poor qualifications are most likely to be out of employment (McDonough and Amick 2001);
- III. **age and position in the life-cycle:** older people who are long-term sick are relatively more likely to be out of employment than the young (Parker 1993; Mutchler, Burr et al. 1999; McDonough and Amick 2001);
- IV. **gender:** although employment rates among women are lower overall, long-term ill-health generally has *less* of an impact on employment for women than men, as women have greater access to part-time or flexible work (Parker 1993; van de Mheen, Stronks et al. 1999; McDonough and Amick 2001); and
- V. **household composition,** as the presence of other adult workers in the household may make it easier for the long-term sick person to leave employment; although equally, the support from

other household members may also be required for the person to remain in employment (Loprest, Rupp et al. 1995; Mutchler, Burr et al. 1999; Johnson and Favereault 2001).

1.3. Research questions

The empirical literature highlights that Pakistanis in the UK have a heavy and premature burden of long-term ill-health, and that long-term sick Pakistanis are a group with disproportionately high rates of unemployment and inactivity. However, it also highlights that the economic impact of long-term ill-health is differentiated across structural and cultural contexts such as class, educational status, age, gender and household composition. This study therefore aims to provide a contextualised and multi-layered account of the experience and consequences of long-term ill-health. The questions guiding the research are as follows:

- I. What is the social process of becoming long-term sick among Pakistanis in the UK? In particular, which factors affect whether an individual comes to regard themselves and be regarded by others as a long-term sick person?
- II. How does long-term ill-health impact upon the livelihoods of Pakistani households in the UK? Which factors affect the economic consequences of long-term ill-health among Pakistanis, and why do they have these effects?
- III. How do UK Pakistani households cope with the economic consequences of long-term ill-health? Which material and immaterial resources are drawn upon in coping with the consequences of long-term ill-health?
- IV. How is the impact of long-term ill-health and coping differentiated within UK Pakistani households, particularly by gender and generation?
- V. How successfully do UK Pakistani households cope with long-term ill-health? What are the emic criteria or signs of coping in the Pakistani community?

1.4. Theoretical orientations and claims

1.4.1. Long-term ill-health within material and cultural contexts

Most of the sociological research on long-term ill-health has focused on subjective and psychological process rather than on the practical consequences of ill-health for individuals. In most of the literature, the classic Parsonian sick role (Parsons 1951) features only as an out-moded model that is criticised for its functionalist examination of the roles of patient and doctor to the exclusion of other social actors, and for its excessive portrayal of the patient as passive and compliant. With long-term conditions, the absence of a cure and the uncertainty about the future prognosis is generally found to reduce the authority of the doctor and the dependence of the patient. The expectation that the person should overcome the condition and resume their pre-illness level of functioning is also criticised as inappropriate; more critical is said to be the issue of adjusting over the long-term (Kasselbaum and Baumann 1965; Segall 1976). In contrast, the chronic illness sociology literature has focused more on the subjective, psychological experience of adjustment, modelled as a 'biographical trajectory' or 'career' replete with direction, goals and turning points. It has explored how long-term sick people come to terms with, cope with and manage their health conditions in everyday life, negotiate their roles actively with health professionals, and try to regain continuity with their sense of self. It has challenged the idea that people necessarily need to take on a sick role, and contributed to the emergence of a politicised ideology of resistance and empowerment in the face of long-term ill-health (see Bury 1982; Charmaz 1983; Williams 1984; Bury 1988; Gerhardt 1990; Bury 1991; Carricaburu and Pierret 1995; Charmaz 2000; Pierret 2003).

However, the accounts of long-term ill-health given by the informants in this study contrasted sharply with the thrust of the chronic illness sociology literature, showing the latter field to be flawed, based on an overly individualistic and decontextualised understanding of peoples' responses. The central themes of 'biographical disruption' had less resonance for the informants, for many of whom the preoccupation with 'loss of self' receded in a broader context of hardship and adversity (see Pound, Gompertz et al. 1998). The priority given to the psychological 'significance' of long-term ill-health was a luxury not afforded to many of the informants, who had to "get on with it" and persist with the practical work of "getting by" in the face of illness. Many lacked the capacity to "take control of" long-term ill-health by educating themselves about their condition and establishing boundaries in interactions with others. I would suggest that the

stress on psychological and subjective process in coming to terms with long-term ill-health may result from the literature's empirical focus on middle-class people, whose capacity to empower themselves and resist the sick role must be understood in relation to their privileged position in society (see also Charmaz 2000; Williams 2000). The accounts here suggest that there is a clear need to understand the experience of long-term ill-health in relation to material contexts and constraints. As Crossley says, "a blanket advocacy of the empowerment perspective actually fails to incorporate sufficient understanding of the structural... aspects of the sick role" (Crossley 1998) (p.508).

An approach which potentially responds to these criticisms is to see long-term ill-health as having a 'social course' in which biological and psychosocial processes act *in tandem with* economic, political and cultural factors (Kleinman and Ware 1992; Kleinman, Wang et al. 1995; Hicks, Kleinman et al. 1998; Hicks and Lam 1999; Ware 1999). Kleinman and colleagues foreground the 'local worlds of experience' in which ill-health is communicated about, negotiated and engaged with as a key influence on experiences of ill-health (Kleinman, Wang et al. 1995). Local worlds are both shared between individuals but also fragmented by factors such as age, gender and social class (Kleinman and Kleinman 1994); and these inflections of local worlds are patterned by structural arrangements of power (Kleinman and Kleinman 1985). In this study, I adopt a 'social course of illness' approach to explore how the subjective experience of ill-health is shaped by interactions and negotiations with other actors – which may encourage resistance and empowerment, or a more public performance of sickness and claiming of entitlements to care, according to the stakes at hand.

I find that it is useful to address the practical consequences of long-term ill-health through the 50-year old concept of the sick role (Parsons 1951) as a conceptual tool to understand the tensions and contradictions that the informants expressed between "taking control of" the health condition, and succumbing to their difficulties and reduced capacities; and between wanting to remain "normal" in their interactions with significant others, and also wanting to have their reduced capacities recognised and responded to. Furthermore, I suggest that ambivalences towards and struggles over the privileges entailed by the sick role are a particularly prominent part of the experience of long-term ill-health when power differentials in individuals' 'local worlds' are marked, as they were for many of the informants.

1.4.2. Livelihoods and the social relations of production

In the poverty literature on the UK, the economic consequences of long-term ill-health have largely been considered in terms of individual employment prospects, in keeping with the focus in research and policy which regards work as the main correlate of, and route out of poverty (Maxwell 1998; Gordon, Adelman et al. 2000). Ill-health may, indeed, have its greatest economic impact through incapacity and foregone earnings. However, the data in this study revealed much more complex dynamics, exposing the emphasis on formal employment as overly reductive and economic. I suggest that a broader conception on livelihoods, defined as “the diverse ways in which people make a living and build their worlds” (Bebbington 1999) (p.2034), is able to counter this narrow specification. Livelihoods approaches were widely used to study poverty in the UK during the 1980s, when the contraction of British industry created high unemployment and forced households to depend less on wage income. Academic attention turned to the portfolio of alternative activities through which households were getting by – particularly the reliance on the assistance of family and community, forms of self-provisioning and unpaid domestic work by women (Pahl 1984; Wallman 1984; Gershuny and Miles 1985; Redclift and Mingione 1985; Pahl 1988; Morris 1990; Dicks, Waddington et al. 1998). The subsequent economic recovery and reduction in unemployment made livelihoods approaches less popular in the literature on the UK in recent years, despite a few rare exceptions (for example Room 2000; Mollona 2005; Orr, Brown et al. 2006). However, their popularity in the international development literature has grown (see J. Harriss 2006; Bernstein 2007 for a critical analysis of why this should be so).

Livelihoods approaches examine poverty at the interface of social structure and individual action and strategy. Households are conceived as resource systems, such that there is a focus on what poor people actually have – how they respond to their circumstances and build on their resources – rather than casting them as passive victims (Rakodi and Lloyd-Jones 2002). To explicate the livelihoods approach, I draw from Wallman’s early but theoretically sophisticated discussion of inner-city London livelihoods (Wallman 1984), which resonates strongly with Bourdieu’s later work on the forms of capital (Bourdieu 1986). As forms of *material* resources, Wallman identifies physical resources, human resources and financial resources, which are equivalent to the conventional model of economic resources as land, labour, capital and the relations between them. She points out that these resources are in some form basic and necessary to livelihoods anywhere: “they are not only material, they are structural; their form and scarcity provide the framework for action by deciding which options are available in a given setting at a given time”

(Wallman 1984) (p.29). In addition, there are *immaterial* social and cultural resources which determine what can be done within the objective structure, and are much more to do with the organisation of the livelihood: “it is these resources that decide what is done with or within the objective structure, and that limit ‘the conditions of possibility’ ... they account for who does better within the constraints of a single environment” (*ibid.* p.29) (I elaborate on the definition of these resources later in the chapter). According to livelihoods approaches, household members survive by drawing upon the range of resources that they possess, which are “the building blocks upon which households are able to undertake production, engage in labour markets, and participate in reciprocal exchanges with other households” (Ellis 2000) (p.31). As this formulation makes clear, households are not closed systems, but survive by using a variety of resources derived from *external* sources. They are linked to wider social and economic institutions through markets, rules and customs, and they are embedded in social networks (Morris 1990). The extra-household linkages constrain as well as set the parameters for householding; social networks are an important source of social control as well as support (Etzioni 1995; 1997).

In this study, I find that it is useful to address the economic impact of long-term ill-health through the concept of the livelihood, which addresses the plethora of monetary and non-monetary activities through which the informants made a living and provisioned themselves outside, or instead of paid employment, and the diverse resources claimed by the informants, which mitigated the economic impact of ill-health. I suggest that the livelihoods approach is well-suited to understanding the local economy of East London, as the households were typically located simultaneously at multiple positions in the structure of production, being property owners earning rents from tenants as well as paid labourers; and engaged in formal employment as well as informal “outside work” or work “on the side”. Furthermore, the livelihoods focus is helpful in putting the *household*, rather than the individual, at the centre of the analysis. In responding to ill-health, this was an important element. Decisions about treatment and coping were negotiated within the household (although as I go on to discuss, not from an equal bargaining position); ill-health costs were incurred by caregivers as well as sick individuals; and the costs fell on the household budget (see Russell 2004).

However, livelihoods approaches also have their limitations, particularly in the extent to which they are able to comprehend the structure of production in which the household is embedded. In their focus on household activities, responses and strategies, livelihoods approaches are strongly

actor-oriented, emphasising the scope for variation at a particular structural position. Correspondingly however, they are weak in their treatment of the institutions of political economy and culture within which households are embedded, which are critical in mediating and constraining their access to resources (see Wood 2003). By implication, livelihoods approaches are also weak in their treatment of power and inequality. Critics have argued that livelihoods approaches say much about the correlates of poverty and precipitating causes of movements into and out of poverty – i.e. the general lack of resources to insure against shocks such as ill-health – but little about “how and why these factors have the effects that they do, in the context of an analysis of the political economy of the locality and of the state” (J. Harriss 2006) (p.17). Livelihoods approaches therefore need to be tempered by “an understanding of poverty in *structural* or *relational* terms, in order to achieve an appropriate emphasis... on the social relations and the inequalities of power that heavily influence the respective trajectories of the better-off and the poor” (Murray 2002) (p.490).

To make sense of the informants’ trajectories after the onset of long-term ill-health, it was necessary for me to analyse their fortunes in relation to their position in the local labour market, and I identify the social relations of work as a central influence on their prospects for retaining or (re)gaining employment. Racism and marginalisation also had important implications for the informants’ employment conditions, and for their ability to secure entitlements from the state in terms of healthcare and welfare; and the material conditions existing in Pakistani networks had implications for the resources that could be garnered through them. I suggest that it is very important not to privilege agency and strategy over the institutional structures that cause long-term ill-health to decimate the livelihoods of particular households. In keeping with other work on urban livelihoods, this study shows that “people are seldom marginal because of their own failings or by simple accident of geography or time. They become and remain marginal because it suits those at the centre that this should be the case” (Staples 2007) (p.16).

1.4.3. Coping strategies and economic polarisation

Most research on poverty in the UK regards long-term ill-health as something that produces a unitary, additive form of disadvantage (see Berthoud 2003; Berthoud and Blekesaune 2006; Clark and Drinkwater 2007). In this study, however, ill-health is exposed to be a process that differentiates and polarizes. There is a recurrent theme in the livelihoods literature that a predictable sequence of coping behaviour exists in response to an economic shock such as ill-

health. 'Coping strategies' – sometimes called subsistence or survival strategies – are “action to manage the costs of an event or process that threatens the welfare of household members, serving to sustain the economic viability of the household” (Russell 2004) (p.151). 'Coping' begins when the household is forced to mobilise resources in order to respond to a crisis; labour is reallocated, savings are liquidated, assets are sold, and loans and gifts are claimed from relatives and friends (Sauerborn, Adams et al. 1996; Adams, Cekan et al. 1998).

In common with other work, the data in this study clearly showed that health shocks were managed differently by households in different economic positions (see Pryer 1987; 1989; 1993; Sauerborn, Adams et al. 1996; Sauerborn, Nougara et al. 1996; Kabir, Rahman et al. 2000; Barrett, Carter et al. 2006). The resources that the households had to draw upon differentiated between the *resilient* and the *vulnerable*. Households with greater initial access to resources, both material and immaterial, were better able to contain and mitigate the economic impact of a shock such as long-term ill-health, whereas resource-poor households were less able to avert crisis and ended up sacrificing both short- and long-term prospects, compromising health and nutrition by ignoring symptoms or rationing consumption, and selling productive assets if they existed. The economic effect of a chronic shock like long-term ill-health was therefore to create *differentiation* or *polarisation* between households.

The livelihoods approach makes explicit the inter-relatedness and inter-convertibility of the resources deployed to cope with economic stress. Depletion of one type of resource had implications for the future reserves and reliance upon other resources; the relative value of the resources possessed by the households was therefore inherently inter-connected. This means that livelihoods are “a framework of non-idiosyncratic covariance, with weakness on one dimension triggering weakness on another with an unravelling affect on livelihood security as a whole” (Wood 2003) (p.457). For example, as financial resources were depleted, the households relied more on informal assistance mediated by reciprocity through ties of kinship-come-friendship. However, the economic constraints on long-term sick households and their inability to repay favours meant that the goodwill of others would eventually be exhausted and the resources that could be garnered through social networks would dry up.

Coping strategies were therefore determined by the structural location of the household and the social networks in which the household is embedded (see also Pahl and Wallace 1985; Morris 1988). More unusually, this study shows that the internal household division of labour influences

the coping strategies that can develop (Redclift 1985; Roldan 1985). An important theme in the literature on post-industrial livelihoods is that households cope with the depletion of their resources by shifting their income-generating activities away from the formal wage economy towards informal work, and further towards the communal and household economies (Gershuny and Miles 1985). In so doing, the data here show that the burden of reproducing the household shifted away from the wage economy and welfare state, and onto the informal economy and the unpaid reproductive work of women and women-centred networks.

1.4.4. Inter-dependence of productive and reproductive work

Livelihoods approaches usually focus only on productive activities, which generate income or goods which ultimately have some kind of monetary value (see Ellis 2000 for an example). However, livelihoods consist of market and non-market elements, and as Whitehead has pointed out, these include reproductive as well as productive activities. One of the often untapped strengths of a livelihoods approach is indeed the potential to treat the productive and reproductive, formal and informal aspects of householding within a single framework (Whitehead 2002). The novelty of this study lies in its treatment of production and reproduction as equally significant parts of the household economy.

Productive and reproductive work within households are linked integrally; particularly for women, for whom paid employment constrains the work of caring and care-giving affects the returns to paid employment in multiple ways (Joshi 2002). Recent changes in the roles and contributions of men and women within households have complicated these links, as have the greater connections between households and the institutions of the welfare state and legal system. The increased entry of women to the workforce has created increases in multiple-role occupancy among women (i.e. the combination of caring and paid work) (Evandrou, Glaser et al. 2002; Evandrou and Glaser 2004). There has been a growing socio-economic polarisation between dual-earning and workless, particularly lone parent households, in accordance with variation in women's education, employment and earning potential (Dex and Joshi 1999; Joshi, Paci et al. 1999). However, in many ways the internal structures of the household economy have changed little in recent years; men have failed to become more involved in the unpaid work of care and household maintenance (Gershuny 2000); there has been continued resistance in state and society to recognising and recompensing the care-giving (Giullari and Lewis 2005); and trends have tended towards an overexploitation of women as the household members responsible

simultaneously for productive and reproductive work (Lewis 2001; Glaser, Evandrou et al. 2005). Thus, whilst the gendered division of labour is changing, it remains true that the relationships between the family and productive system – and the state – account for the conditions of female participation in production (Redclift 1985).

To get a handle on the economic impact of long-term ill-health, I found it essential to examine reproduction alongside production. The economic significance of reproductive work in freeing up time for other household members to engage in production was in most cases invisible, and the principal care-givers often struggled to have their work appreciated and recognised by others. However, the poorest households were actually those in which female care-givers were severely incapacitated – making it difficult to maintain household consumption needs or everyday reproductive activities, emphasising the significance of reproductive work for the overall welfare of the household's members. The informants prioritised production and male careers, and male ill-health usually presented a further-reaching shock to the household economy. However, within extended kinship networks, certain female careers were also prioritised, meaning that certain women – who in Chapter 8 I call 'meta-carers' – came to specialise in and take over the work of caring for a constellation of households, whose livelihoods became inherently interconnected.

1.4.5. Intra-household differentiation in the impact of long-term ill-health

Differentiation within the household in terms of the roles, resources and bargaining power of individual household members all influenced household coping capacity, and determined patterns of poverty within households. To understand these processes, I turn to a growing body of work by heterodox economists critiquing the standard economic models of the household, as exemplified by Becker's 'new household economics', as invalid. According to Becker, the household is a corporate entity in which a single decision-maker makes altruistic decisions to maximise collective wellbeing (Becker 1981). By contrast, heterodox approaches characterize intra-household interactions as some form of 'bargaining' or 'cooperative conflict' in which household members are seen to have both *joint* and *separate* interests (Whitehead 1981; Pahl 1983; Sen 1984; Folbre 1986; Brannen and Wilson 1987; Bruce 1989; Morris 1990; Sen 1990; Kabeer 1994; Whitehead and Kabeer 2001).

Whilst 'bargaining' approaches are certainly an improvement on standard economic models, I argue that there are a number of key dimensions that are neglected in the literature. First, intra-

household dynamics must be understood as embedded in extra-household institutions. The intra-household allocation and control of resources vary systematically in accordance with occupational class; the wider gender system also has a strong influence. In this study, female seclusion or *pardah* particularly curtailed women's engagement with paid work, restricting them to income-earning activities which were carried out within the home and complied with seclusion. Occupational segregation by gender in the labour market impacted upon household strategic options, foreclosing some options while making others more available. Second, as Agarwal also argues, bargaining approaches give an insufficiently nuanced formulation of power within households, failing to capture the complexity of the determinants of bargaining power, how these are contested, and how socio-cultural norms set the limit over what can be bargained over (Agarwal 1997). Importantly, women may work to secure their own interests within patriarchal norms of self-subordination, drawing on the reciprocity of claims and obligations, power and responsibility. Whilst it is true that household members are bound together by material interests, it is important not to ignore the powerful affective qualities with which kinship and household membership are imbued, which emerged as key to these dynamics (Carsten 1997; 2000; Peletz 2001; Yan 2001; Carsten 2004). Whilst the analysis here emphasises the functions of relationships and the uses to which they are put – what Bourdieu calls 'practical kinship' (Bourdieu 1977) – I avoid the excessive instrumentalism and reductionism associated with this approach by examining closely the affective dynamics in the data.

In this study, women were found to bear a disproportionate brunt of the costs of coping strategies. Women tended to have weaker claims to assets than men; they had less access to labour markets and suffered wage differentials in employment; they provided additional household resources more often than men; they liquidated their own resources more readily to increase household income; and they took the main responsibility for children (see Laier, Davies et al. 1996). Whilst reducing the vulnerability of the household overall, intra-household labour substitutions tended to overburden female household members (see Moser 1998). Labour was reallocated from reproductive work to paid employment, but subject to a constraint on male involvement in domestic duties which transformed women into income earners who were still primarily responsible for reproducing the household. As Masika and Joekes suggest, patriarchal culture has major implications for the coping strategies that may be adopted:

“...coping is harder with very tight gender divisions of labour. In crisis, both women and men may be barred from pursuing particular strategies which are not habitually regarded as part of

their domain. Where female seclusion is central to the framing of the household division of labour, women's coping options are particularly constrained. [To cope with economic crisis] women and men need to be able to combine productive and reproductive roles.”
(Masika and Joeckes 1996) (p.12)

1.4.6. Resistance and asserting social status

As Wallman points out, according to official criteria, the most successful coping strategy would be the one that puts least strain on the statutory services (Wallman 1984) – namely, the households who manage to remain in employment and support themselves through the balanced use of their portfolio of resources. However, the informants' own objectives were far more complex and multi-dimensional. Coping strategies were not oriented purely towards economic values, but towards a broader concept of 'success', defined by Werbner as “the competitive achievement of prestige or honour, and of the symbolic goods signalling these, within a specific regime of value” (Werbner 1999) (p.551). They had their own criteria for evaluating social standing, often based on self-reliance, forms of conspicuous consumption and 'ethnic intensification' through upholding traditions, reproductive rituals or bringing up children well. These 'cultural resources' presented ways of resisting the potentially ruinous consequences of long-term ill-health for long-term status and self-esteem, despite the downward economic trajectory into which many of the households had become locked. Impoverishment was therefore a trigger for the informants to transform their lives by investing in socio-cultural values. The informants' tensions between impoverishment and asserting social status are usefully captured by Tsing's formulation of marginalisation as a “placement that makes evident both the constraining, oppressive quality of cultural exclusion and the creative potential of rearticulating, enlivening, and rearranging the very social categories that peripheralise a group's existence” (Tsing 1994) (p.279).

It is tempting to see the informants' actions in resisting the moral consequences of long-term ill-health and impoverishment as a particular 'ethnic' or 'cultural resource' of Pakistanis. Ballard, for example, proposes that Asians have been uniquely able to challenge the negative self-image entailed by their incorporation into the bottom of the British class system by claiming social status on the basis of their own, internal ranking systems (Ballard 1992). However, as I elaborate in the next section of this chapter, this would reproduce a fallacious stereotype that some ethnic groups are somehow 'more ethnic' or 'more cultural' than others. 'Cultural resistance' to material

poverty via investment in prestige or honour is surely not particular to a single ethnic group, but a widespread practice that takes on local forms: “strategic action to keep a family’s place in the social order, a cultural performance with the objective of maintaining respectability and holding on to moral, as well as financial, capital” (Kleinman, Wang et al. 1995) (p.1327). It is therefore important to examine the ‘specific regime of value’ that underlies action locally, as ‘irrational’, ‘non-economic’ behaviour may be apprehended, as Bourdieu explicates, as a ‘sensible bluff’ (Bourdieu 1977) – allowing the accumulation of symbolic power which can later be inter-converted into economic capital through social relations, linking together the households’ means of production, consumption and reproduction as a multi-dimensional, multi-layered signifier of relative social standing.

1.4.7. Ethnicity, structure and agency

Much of the research on ethnicity and health has been undertaken within the public health tradition, and treats ethnic groups as objective, discrete divisions of the population (see Bradby 1995; 2003). Latterly, critical strands of the literature have argued for a need to reconceptualise ethnicity in line with developments in sociology (Smaje 1995; 1996; 1997; Fenton and Charsley 2000; Smaje 2000a). In sociological theory, concerns with ethnic ‘groups’ and ‘boundaries’ have been rejected as essentialising, and the gaze has shifted to the subjective processes through which ethnic identity is constructed, recognising that ethnicity is only one of multiple subject positions. Hall’s work has been particularly seminal in advancing an understanding of ethnicity as constituted and re-made through a never-ending process of ‘becoming’, such that identities are never ‘achieved’ (completed or finished); rather, they are constructed and asserted in different ways, across different contexts and time (Hall 1992). However, theory has been criticised for retreating into “a morally pure high ground untainted by the messy and incommensurable realities of empirical data” (Alexander 2002) (p.561). The celebration of self-defining difference has tended to lose sight of the constraints on the capacity of individuals to shape their own identities; Hall’s central insight into the centrality of “history, language and culture in the construction of subjectivity and identity” (Hall 1992) (p.257). In shying away from such constraints, sociological theory has become increasingly uncomfortable with the realities of material inequality and racism. Empirical data show that people continue to subscribe to what Baumann calls a ‘dominant discourse’ associating ethnic identities with particular groups or communities, whilst also denying the congruence of the two:

“they are thus not the dupes of the dominant discourse, but neither are they the post-modern champions of a cult which worships ‘hybridity’ or ‘border zones’ for their own sense... [they] develop their discursive competencies in close connections with the social facts of everyday life and they cultivate fine judgements of when to use what discourse in which situation”

(Baumann 1996) (p.204)

As a field that is principally concerned with understanding materiality, the difficulties of reconciling the shifting and contextual qualities of ethnic identity with its grounded realities raises particular problems for research on ethnicity and health. In an invaluable contribution to the ethnicity and health literature, Smaje argues that there is a need to examine the *content* of processes of identity construction, beyond the negative critique of ethnicity as ‘just a social construct’ (Smaje 1997; 2000a). Given that patterns emerge around ethnic groups when health and social inequalities are examined, and that people act as if ethnic categories exist, it is important to take seriously the emergent or experiential qualities of ethnic identity (i.e. the affective claims by which we distinguish between ‘us’ and ‘them’ and identify a collectivity with which there is a sense of belonging). Rather than persist with this well-worn to-ing and fro-ing between the objective vs. the subjective qualities of ethnic identity, I would argue for a need to re-frame the debate.

Following various theoretical commentaries (Bentley 1987; Moi 1991; Smaje 1995; 1997) I find it useful to view ethnicity in terms of Bourdieu’s concept of social practice (Bourdieu 1977). In this formulation, ethnicity is a property of individuals which emerges in particular contexts and circumstances through their own actions and those of others. It is a facet of a person’s socially-structured subjectivity, set by the limits of the ‘habitus’ or the set of tendencies which organise people’s social, spatial, temporal and affective orientations to the world. The ‘practical sense’ which a social order produces in its members underpins their adherence to the social order by ‘naturalising’ some aspects of reality, placing the behaviour associated with them in the realm of unquestioned routine, habit and tradition. Understanding an ‘unreflective ethnicity’ in terms of differences and similarities in the ‘habitus’ allows us to see ethnicity as the product of the positioning of groups in “the objective classes, i.e. the divisions by sex, age, or position in the relations of production” (Bourdieu 1977) (p.164). However, it also allows us to retain sight of the ‘emergent’ social meanings that people construct through the idiom of ethnicity in their everyday lives; grasping the practice of ethnicity from the inside, “within the very movement of [its] accomplishment” (*ibid.* p.3). This formulation of ethnicity allows us to see structure and agency,

the objective and subjective qualities of ethnic identity, as *relational* processes; as Brah says, “enmeshing subject positions and collective identities” (Brah 1996) (p.65).

In this study, ethnicity emerged as a facet of the informants’ lives proxying for a more encompassing process of material differentiation between groups. In the quantitative component of the study, an appreciable part of the ethnic differences in livelihood outcomes following the onset of long-term ill-health could be attributed to socio-economic, household and familial differences between the ethnic groups. In the qualitative part of the study, the increasingly differentiated position of Pakistanis in the economy of East London was a strong determinant of the long-term sick informants’ capacity to retain and (re)gain employment. However, the analysis stands short of showing ethnicity merely as an ‘empty vessel’ or mystification of the social structure of production. The ethnographic study also captured the social meanings and content of Pakistani ethnicity and the implications it had for livelihoods. Evidently, the signifiers of co-identification were shifting and contextual; shared Pakistani identity was meaningful, but so were more inclusive and exclusive categories such as Asian, Kashmiri and Punjabi, as well as other social identities. Moreover, the social meanings of Pakistani ethnicity varied in accordance with social class and gender, as people with a higher class position were less reliant on co-ethnic ties – although higher class status could also be associated with ‘ethnic intensification’ or an *increased* commitment to constructions of tradition and Islamic religiosity, in keeping with upper-class religious identities in Pakistan – and there were stronger expectations for women to perform ethnic identity than men. ‘Ethnicity as practice’ is therefore a tool to understand the contextual and variable influence of ethnicity. In Bourdieu’s analysis, social categories are always relational, so that the power they carry is determined by their fluctuating relationship to other categories: “when the analysis is conducted variable by variable, there is a danger of attributing to one of the variables (such as sex or age, each of which may express in its own way the whole situation or trend of a class) the effect of the *set* of variables” (Bourdieu 1984) (p.105-6).

1.4.8. Culture

The ethnicity and health literature tends to conflate culture with ethnic group. Benson’s wry observation that ‘Asians have culture, West Indians have problems’ (Benson 1996), a comment on the disciplinary division of labour between work on South Asians vs. work on Afro-Caribbean minorities in the UK and the explanatory power of notions of cultural authenticity vs. racism, is reflected within the ethnicity and health field. For South Asians, ethno-religious cultures

differentiating health beliefs, lifestyle and health management, have been emphasised and found to be important in understanding their poorer health. The focus has been on areas of exotic divergence from biomedicine, such as spiritual attributions of disease or ayurvedic classificatory systems of diet (for examples see Kelleher and Hillier 1996; Greenhalgh, Helman et al. 1998; Chowdhury, Helman et al. 2000; Jobanputra and Furnham 2005; Spiro 2005). Culture has been cast as a property confined to a particular group, and has consequently ossified and essentialised, overlooking heterogeneity within ethnic minority groups as well as the cross-cutting of cultural practices across ethnic groups (for exceptions see Lambert and Sevak 1996; Bradby 1997; Prior, Chun et al. 2000; Reed 2000). However, elsewhere in sociology and anthropology, representations of culture in terms of bounded traditions, ritual and custom are dead in the pan, and there is a consensus in that culture should be understood as the construction of meaning. It is no longer tenable to treat culture as timeless, homogeneous and shared. The question remains, however, as to how we are to understand culture.

Bourdieu defines culture in terms of social practice: the habitus, the patterning of sensibility, and the everyday activities of living (Bourdieu 1977). This formulation emphasises the role of individuals in 'making culture' rather than 'having culture', and implies a shift away from the notion of 'ethnic culture' towards seeing culture in terms of specific practices which may cut across ethnic groups (Smaje 2000b). It allows us to develop a flexible, concrete and non-static understanding of culture that is useful in understanding material processes such as ill-health and impoverishment. For example, it is more common for Pakistanis to live in extended families than for the White majority in the UK. However, extended living is not confined to Pakistanis, and the types of experience that flow from this particular family form are not exclusive to them. Ethnic differences in family composition may therefore be apprehended as statistical or probabilistic norms, which are, furthermore, embedded in structural and material conditions.

However, this deconstructionist formulation of culture has difficulties in apprehending the importance of normative or aspired cultural ideologies, ideals of authenticity and tradition and their centrality to the performance of ethnic identity – and in the field, I found that these types of normative processes had a force of their own. To reconcile these multifarious manifestations of culture I turn to the Comaroffs, who develop a Gramscian version of cultural politics. For the Comaroffs, culture contains within it multiple ideologies, which are differentially empowered: "some will be woven into more or less tightly integrated, relatively explicit worldviews; others may be heavily contested, the stuff of counter-ideologies and 'subcultures'; yet others may

become more or less unfixed, relatively freefloating, and indeterminate in their value and meaning” (Comaroff and Comaroff 1992) (p.27). The dominance of certain cultural meanings over others is a matter of power relations. However, they argue that power cannot ever be meaningfully abstracted from culture. Indeed, for the Comaroffs ideology can itself be seen as a form of power working in a *non-agentive* manner, shaping perceptions and practices: “its effects are internalised: in their negative guise, as *constraints*; in their neutral guise, as *conventions*; in their positive guise, as *values*” (*ibid.* p.28). This view of culture is important to bear in mind, as it captures the paradoxical qualities of the talk about culture that follow in the informants’ accounts. Culture was at once probabilistic, but also aspired: as the Comaroffs put it, “coherent yet chaotic, authoritative yet arguable, highly systemic yet unpredictable, consensual yet internally contradictory” (*ibid.* p.28).

1.4.9. Inclusion and exclusion

There is an influential body of work understanding ethnicity in terms of social or cultural capital (Portes and Sensenbrenner 1993; Portes and Landolt 1996; Portes 1998; Modood 2004; Loury, Modood et al. 2005). The hugely varied use of the term social capital is unhelpful, particularly its dual use in terms of individual social resources and as a characteristic of communities as a whole (Coleman 1990; Putnam 1993). In this study, social capital is understood in Bourdieu’s terms as ‘relational power’ (Bourdieu 1986), or the resources that can be accessed informally via social ties and networks based on mutual acquaintance and interests. However, I also explore how the resources accessed through social ties are influenced by membership of particular ethnic, class-based and geographic communities. The concept of ‘cultural capital’ also derives from Bourdieu, for whom it represented knowledge accumulated through upbringing and education that confers a particular social status or distinction (Bourdieu 1986). However, the concept has broader application when understood in terms of codes of inclusion and exclusion, and not merely as the preserve of elite groups. Social and cultural capitals are identified as key resources for migrant or ethnic minority groups, offering the possibility for lifting people out of poverty through collective economic organisation. As it has been formulated in the literature, trust is a resource held in co-ethnic networks, which enables people to bridge the risks inherent in making relationships and exchanges with others (Gambetta 1988). Overtly, therefore, trust is the assurance that comes from shared norms, reciprocity and egalitarianism (Fukuyama 1995). Trust between co-ethnics provides cumulative know-how and smoothens credit relations; privileges employment opportunities with co-ethnic employers; potentates productive exchanges outside a hostile

mainstream White economy; and constitutes a pool of consumers from which an ethnic entrepreneur may create value from nothing (Werbner 1999; 2001).

In this study, ethnic identity was found to function as an informal code for inclusion in co-ethnic networks through which information, favours and opportunities were channelled, affecting access to healthcare, the welfare state and employment opportunities. However, the value of co-ethnic networks could not be abstracted from the disadvantage incurred by exclusion from White society. The bounded solidarity potentiated by Pakistani ethnicity was therefore double-edged; co-ethnic networks were an ambivalent resource. Co-ethnic networks privileged access to opportunities within certain economic sectors, but simultaneously constrained the range of occupations that were considered within reach, and frequently entailed prejudicial terms of employment. They tended to secure access to low-skilled work in small businesses, and precluded access to jobs outside the ethnic economy.

Pakistani ethnicity also signalled as a cue for behavioural expectations by the wider Pakistani society (*maashra*), which made claims over its members, and with which the informants had to negotiate or accommodate. However, the close-knit nature of the *maashra* functioned as a source of social control and constrained the possibilities that the informants could contemplate. The 'moral voice' (Etzioni 1995; 1997) through which the community laid claim on its members ensured compliance with normative values. Where networks were dominated by gender segregation and comprised by predominantly same-sex peer groups, rules and sanctions concerning gender roles were quick to be enforced, and individuals who stepped outside of their normative gender roles came to be excluded from certain productive networks.

Proponents have long recognised that social capital has its 'downside' (Portes and Landolt 1996); whether social capital it 'pulls you up' or 'keeps you down' depends on the patterns and structures of the group, and the kinds of resources that can be accessed through within-group ties. Beyond this, however, a missing dimension of the social capital paradigm is the appreciation of power relations *within* co-ethnic networks. Networks can be as much about power as they are about solidarity: "what appears to indicate trust may be largely a consequence of domination or lack of alternatives, or simple mutual dependency" (Sayer 2001) (p.699). The informants' trajectories in the face of long-term ill-health question the assumption that marginalised people to lift themselves up on the strength of their own networks (see Fine 2001; J. Harriss 2001). In keeping with other work criticising the prominence of social capital within the study of poverty,

the data here suggest the need for a more nuanced and contextual analysis of networks that “traces the way in which networks have been shaped, not simply by cultural identity, but by history, power relations and relations with the state” (Meagher 2005) (p.232).

1.5. Organisation of the thesis

As outlined above, the present study focuses on the concept of livelihoods, which are both a grounded reality in people’s lives, but also multi-dimensional, dynamic and elusive. As such, livelihoods need to be captured using a combination of quantitative and qualitative research methods. Mixed methods are able to provide confirmatory or complementary perspectives (Baum 1995; Morgan 1998). As Wallman and Baker point out, a multi-layered and multi-disciplinary research scheme has greater potential scope for triangulation, providing optimal conditions for challenging any overly-facile interpretation of the data. The advantages of combining different approaches are also incremental: “description is better thick than thin” (Wallman and Baker 1996) (p.678). However, quantitative and qualitative perspectives are by no means easy to integrate. Qualitative research “is sceptical about the status of social facts, and, against ‘discrete’ variables, sees social life as a constituted whole which cannot sensibly be deconstituted” (Fenton and Charsley 2000). For this reason, I have separated this thesis into its quantitative and qualitative components, although I attempt to integrate the quantitative and qualitative findings by interrogating each component of the study in the light of the other.

The thesis begins with the quantitative component of the study. **Chapter 2** introduces the quantitative design and methods. **Chapter 3** then chiefly addresses the first two research questions, exploring quantitatively the social factors behind the heavy burden of long-term ill-health among Pakistanis, the livelihoods of long-term sick Pakistanis, and the relationships between long-term ill-health and livelihoods across ethnic groups. It also provides context for the subsequent chapters, in analysing how the associations between long-term ill-health and livelihoods are differentiated in accordance with social factors.

Chapter 4 then moves into the qualitative component of the study, making explicit the multiple methods that were used to collect data in East London, and the process of analysis. It provides context into the history of migration and settlement, and the economic structures of the Pakistani population in the East End. **Chapter 5** sets the context by exploring the factors that shape whether a person with long-term ill-health comes to regard themselves and be regarded by others

as a sick person. The remaining empirical chapters are then structured around the household processes of production, consumption and reproduction. **Chapter 6** addresses the impact of long-term ill-health on employment, within the context of the local labour market and claims and entitlements from the state. **Chapter 7** goes on to look at intra-household labour substitution and the diverse economic activities through which households affected by long-term ill-health make a living outside or instead of paid employment, as well as the consumption strategies that households engage in to ensure the reproduction of the family at a given level of income. **Chapter 8** then adopts a life-course approach and addresses the impact of long-term ill-health on the reproduction of the household both in the everyday and inter-generationally. **Chapter 9** concludes the thesis, integrating the quantitative and qualitative findings, revisiting the issues raised in this introduction, and drawing out the wider implications of the study.

Chapter 2: Quantitative methods

2.1. Introduction

As Kirkwood and Sterne note, “the purpose of a statistical analysis is to provide a simplified but useful picture of reality” (Kirkwood and Sterne 2003) (p.466). The quantitative component of the study provides the bare bones of descriptive information about the socio-economic predicaments of Pakistani individuals and households affected by long-term ill-health. It also permits an exploration of the relationships between long-term ill-health and some of the more tangible dimensions of livelihoods among Pakistanis, and an assessment of whether these relationships are statistically different compared with other ethnic groups; the inter-ethnic comparisons are informative because they set benchmarks against which to interpret the data on Pakistanis. The quantitative analysis considers the inter-relationships between Pakistani ethnicity and cross-cutting factors such as age, sex, educational status, occupational class and housing tenure, to explore variation within the ethnic groups and the extent to which ethnic group might influence outcomes via these cross-cutting factors. As Chapter 1 outlined, there is a need for conceptual clarity on “how, where, why, and under what circumstances” (Archer 2003) (p.20) ethnicity comes to be important in the patterning of ill-health and its impact on livelihoods.

2.2. Datasets

I used two quantitative datasets. First, I used the Labour Force Survey (LFS) to analyse the individual-level relationships between (i) long-term ill-health, (ii) economic activity and (iii) the receipt of Disability Living Allowance. The LFS was chosen because of the detail of its questions on long-term ill-health and because of its large sample size. The LFS is a survey of private households, carried out to provide information on the labour market in the UK. It is conducted every quarter, and contains a semi-panel element whereby each respondent is surveyed for five consecutive ‘waves’ (quarters) (ONS 2003). The LFS covers around 55,000 households and 130,000 individual respondents at each quarter, of whom approximately 60,000 are of working age (women aged 18-59 and men aged 18-64). To ensure sufficient numbers of ethnic minority respondents, I pooled 12 quarters of the LFS from 2002-05. As the LFS uses a single-stage random sampling design, there was no need to weight the analysis to scale up the sample estimates to the level of the population.

Second, I used the household file of the Labour Force Survey (HLFS) to analyse (i) the composition of households containing working-age individuals with long-term ill-health, and: (ii) the relationships between long-term ill-health and economic activity at the household level. The household file covers approximately 55,000 households at each quarter and is available for the spring and autumn quarters of each year. I pooled six quarters from 2002-04 to ensure sufficient numbers of ethnic minority households. After deriving variables to summarise the characteristics of all the household members, I reduced the dataset to the household reference person so that there would be just one record per household. The dataset comprised 234,240 households containing working-age adults, or 192,330 multiple-person working-age households.

2.3. Operationalisation of key concepts

2.3.1. Long-term ill-health

Survey items on ‘limiting long-term ill-health’ have been validated and shown to be robustly associated with other measures, including self-reported general health, self-reports of common conditions, clinical diagnosis, the frequency of GP consultations, and mortality (Cohen, Forbes et al. 1995; Jordan, Ong et al. 2000; Payne and Saul 2000; Manor, Matthews et al. 2001). The LFS questions distinguish between long-term ill-health and functional ability:

- I. **‘Long-term ill-health’** was indicated by the response to the question: “do you have any health problems or disabilities that you expect will last for more than a year?”.
- II. **‘Activity limitations’**. Functional ability was indicated by the response to the follow-up question: “do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day-to-day activities?”. The respondent is prompted that: “if you are receiving medication or treatment, please consider what the situation would be without the medication or treatment”.
- III. **‘Number of long-term health conditions’**. The question “do you have...” is followed by a list of 17 types of health problems or disabilities, then “which of these is your main health problem or disability?”. I summed the number of health conditions reported by the respondent to provide another proxy to capture underlying variation in the severity of the person’s health.

Unfortunately, unlike other recent surveys, the LFS does not yet have an item on caring. However, I used the HLFS to identify households containing long-term sick working-age adults, to investigate the circumstances of other household members might be involved in providing care.

2.3.2. Ethnicity

Surveys are not well-placed to capture the complex, non-exclusive and situational nature of ethnicity. Rather, they ask respondents to choose between a selection of 'ethnic groups', therefore treating ethnic categories as exclusive, fixed populations (Bradby 2003). The LFS uses the 2001 census ONS question on ethnic group (see Aspinall 2000). I reduced the responses to eight categories to make the analysis and interpretation more manageable: White British, Indian, Pakistani, Bangladeshi, Black Caribbean, Black African, Chinese and Mixed/other. These were well-defined categories with sufficiently large samples to generate meaningful comparisons.

In the analysis of the HLFS, I used the ethnic group of the 'household reference person' as a proxy for the entire household, although this is obviously problematic as it conceals potentially important variation in ethnic group within mixed households.

2.3.3. Livelihood outcomes

The choice of livelihood outcomes was guided by the insights gained from the qualitative work concerning the most important, observable and measurable elements of livelihoods and how they inter-related with ill-health at the level of the individual and household.

- I. **Economic activity status** was derived from the question "did you do any paid work in the week ending [date of reference week], either as an employee or as self-employed?". From this question the International Labour Organisation classifications of economic activity were derived, which distinguish between three exclusive categories: paid employment, ILO unemployment and inactivity. As well as people who are long-term sick or disabled, the inactive category includes full-time students, people who are looking after family or home, temporarily sick or injured, or not looking for work for other reasons.
- II. **Receipt of welfare benefits** was indicated by the question "in the week ending [date of reference week], were you claiming...". I examined Disability Living Allowance (DLA) as it is intended to offset the economic costs of long-term ill-health. DLA is an important benefit

because it is not means-tested or affected by employment status, and anyone with 'severe physical or mental illness or disability' who is below 65 years is eligible to claim it. I did not examine Incapacity Benefit (IB), as its eligibility criteria were too complex to be captured effectively by the LFS. IB eligibility depends on past economic activity and National Insurance contributions, and where eligible, dependents' allowances are incorporated into a single benefit entitlement, which means that long-term sick women may receive financial support as a dependent of a partner receiving IB rather than individually. However, IB receipt and ethnic group has been analysed by Platt (Salway, Platt et al. 2007). I did not examine Disabled Person's Tax Credit as it was reported by too few of the respondents (145 or 0.02% of the dataset). Data on Carer's Allowance is not collected in the LFS.

- III. **Workless household.** In the HLFS I used the economic activity variable to identify households with no working-age adults in employment. I also created a further variable with exclusive categories distinguishing between workless households in which all the working-age adults were economically inactive; all were unemployed; and those in which some adults were economically inactive and some were unemployed.
- IV. **Household composition.** In the HLFS I used the list of household members and classed household composition into seven categories: single persons, couples without children, couples with dependent children, couples with non-dependent children, lone parents with dependent children, lone parents with non-dependent children, and complex (multiple-family) households. I also derived variables to identify the presence of elderly people in the households (i.e. women above 60 years and men above 65 years) and the presence of children below 15 years.

I did not examine pay as it was only asked in the first and fifth waves of the LFS, was often missing, and would have required constructing a new dataset and reducing the amount of data on the ethnic minority respondents. However, analyses of pay, long-term ill-health and ethnic group exist in the literature (Szczepura, Gumber et al. 2004; Salway, Platt et al. 2007).

2.3.4. Background characteristics

The following factors are associated independently by long-term ill-health, ethnic group and the livelihood outcomes (economic activity and DLA receipt) and therefore needed to be taken into account in the multivariate analysis to examine whether part of the observed associations might be attributed to other factors that are confounding or potentially on the 'causal pathway'. As I

outlined in Chapter 1, differential associations between long-term ill-health and economic activity have been identified, so these factors also needed to be tested for interactions.

- I. **Age and sex.** Long-term ill-health increases with age, and older people are less likely to be economically active. Women report higher levels of ill-health than men, particularly at older ages, and men and women have very different economic activity profiles. The distribution of age and sex also varies between ethnic groups. Age squared was also included to test for non-linear effects of age. I tested that age squared would be the best approximation to the non-linear effects of age by comparing the fit between age squared graphically with a fit using fractional polynomials. The quadratic fitted the data well in all cases.
- II. **Education** was indicated by the highest level of qualification held: degree or higher level diploma, NVQ level 3 or trade apprenticeships, NVQ level 2, NVQ level 1 or below, other qualifications (including overseas qualifications), and no qualifications. In the household analysis, the education of the household reference person was used as a proxy, although this simplifies more complex variation in education within households. Generally, people with lower qualifications are more likely to have long-term ill-health, are less likely to be economically active but more likely to receive DLA. Educational status also varies substantially between ethnic groups.
- III. **Occupational class** was indicated by the National Statistics Socio-Economic Class (NSSEC), which is a recently validated categorisation of occupational class, broadly retaining a conception of class in terms of an individual's position in relations of production (Rose and Pevalin 2001). I divided it into: managerial and professional occupations, intermediate occupations, routine and manual occupations, people who have never worked or are long-term unemployed, and full-time students. People from lower class backgrounds are more likely to have long-term ill-health, are less likely to be economically active, but more likely to receive DLA. Occupational class also varies substantially between ethnic groups. Unfortunately, the analysis of occupational class was not very satisfactory as 9% of the NSSEC data were missing. There were also large numbers of people whose occupational class could not be identified due to never working or long-term unemployment (see Appendices 1 and 2), which prevented me from using NSSEC in the analysis of economic activity as the group who had never worked or were long-term unemployed was endogenous to the outcome variable.
- IV. **Housing tenure**, which was divided into: owner occupied accommodation, privately rented and rented from the local authority or housing association. People in privately rented or social

housing are more likely to have long-term ill-health and less likely to be economically active than owner occupiers, and housing tenure also varies substantially between ethnic groups.

The following factors were explored as potential confounders, but not for interactions:

- V. **Regional quarterly unemployment rate and region.** Long-term ill-health, ethnic groups and local economic decline are distributed differently across the country, and therefore potentially confound the relationships between long-term ill-health and economic activity status or benefit receipt (Simpson, Purdam et al. 2006).
- VI. **Other welfare benefits,** namely Income Support and unemployment benefits or National Insurance credits. People who were in receipt of other benefits might be 'passported' onto DLA due to their familiarity with the system (Noble, Platt et al. 1997).
- VII. **Having a partner,** as single adults have poorer health as well as low rates of employment, whereas having a partner is associated with working among men (Berthoud 2003).
- VIII. **Children under the age of five in the family,** as the presence of young children is associated with low levels of employment, particularly for women (Berthoud 2003).
- IX. **Household characteristics such as numbers of household members, household composition (using the groupings defined in section 2.2.2.3.), elderly person(s) and child(ren) under 15 years** were also explored because large numbers of household members, particularly dependants, are associated with household worklessness (Walling 2004).

2.4. Data analysis

The statistical package Stata 9.0 was used to analyse the data. Stata has a set of commands called the 'svy' or the 'cluster' commands, which take into account the lack of independence of individual observations within clusters (StataCorp 2005). I used these to account for the repeated observations on individuals resulting from the pooling, and to ensure that the standard errors were not artificially inflated and did not overestimate the statistical significance of the associations.

- I. **Cross-tabulations and graphs.** I produced descriptive statistics on the levels of long-term ill-health and the livelihood outcomes. These statistics were produced separately for the different ethnic groups, by sex and then by age. Tables containing these descriptive statistics are presented in Appendices 1, 2 and 3. I also explored how household composition, education, occupational class and housing tenure varied along with long-term ill-health and activity

limitations and the livelihood outcomes. For categorical variables the X^2 statistic was calculated to measure the significance of the overall associations obtained.

- II. **Multivariate analysis** was used to explore the associations between long-term ill-health and economic activity or DLA receipt, controlling for variation in other relevant characteristics. First, I used Mantel-Haenszel X^2 tests to examine confounding and identify potential interactions between long-term ill-health and other variables, although the bivariate analyses were not very informative as many of the associations were strongly confounded by age. I then used multiple regression to control for multiple potential confounding variables. I used binary logistic regression when the outcome was a dichotomous variable (as for household worklessness and DLA receipt) and multinomial logistic regression where the outcome consisted of more than two categories (as economic activity, which was divided into paid work, unemployment and economic inactivity). I constructed the regression models in a forward step-wise sequential manner to reduce multi-collinearity between the different variables and to identify the contribution of each variable to the overall model (Norušis 2002). I examined the Wald statistics to test whether individual odds ratios were significantly different from one. After running the regression, I used additional Wald tests to test the significance of the variables to the overall model. Since it is not possible to perform the likelihood ratio test after using the 'cluster' command in the regressions, I had to re-run the regressions using un-clustered data to examine the significance of the variables to the likelihood of the overall model. I also examined the pseudo R² values to establish whether a good extent of variation in the outcome was being captured by the models (25% of the variance).
- III. **Interactions.** I explored whether the associations between long-term ill-health and the livelihood outcomes were differentiated by a number of social factors such as ethnic group. I tested for interaction effects by examining the Wald statistics for the individual interaction parameters in the multivariate regression models, and carrying out a post-estimation Wald test to examine the statistical significance of entire groups of interaction terms (Kirkwood and Sterne 2003). Since it was impossible to use the likelihood ratio test on the clustered data, I had to re-run the regressions on the un-clustered data to examine the significance of the contribution of the interaction to the likelihood of the overall model. Identifying interaction effects was difficult because of the low power of the Wald test, and because the models often contained multiple tests and involved a large number of terms. When the tests indicated that statistically significant interactions were present in the data, I generated dummy interaction variables to illustrate more clearly the direction and scale of the interactions that were found.

IV. **Predicted probabilities.** ‘Predict’ is a post-estimation command in Stata which generates a prediction of the probability of the outcome for every case in the sample, based on the model that has just been run. The probabilities can be calculated to summarise the variation in the probability of the outcome according to a particular factor, holding the other characteristics in the model constant (StataCorp 2005). In exploring the ethnic differentials in DLA receipt, I used the ‘adjust’ as well as ‘predict’. ‘Adjust’ allowed me to generate predicted probabilities for cases that might not have been in the data – for example, 20 year old Pakistani women with activity limitations who were in receipt of DLA. In the ‘adjust’ command the values for the other variables in the model have to be manually constrained. This analysis produced predicted probabilities of DLA receipt for different ethnic groups, based on fictive cases which I set to have average characteristics with respect to the other variables in the model.

2.5. Limitations in the quantitative component

There were three specific limitations in the quantitative component of the study:

- I. **Lack of longitudinal analysis.** The analysis is based on cross-sectional data, and is therefore unable to distinguish the temporal direction of the association. For example, if long-term ill-health is found to be associated with economic activity, it is impossible to distinguish between the impact of health on employment, and the fact that unemployment or economic inactivity makes people prone to becoming long-term sick. In some cases it is possible to use the LFS for longitudinal analysis because the five-wave survey design provides a quasi-panel study. However, exploratory analysis indicated little change in long-term ill-health between the panels, and that yearly quarters was too short a period to track meaningful changes in economic activity in relation to changes in health. I also explored the possibility of carrying out genuinely longitudinal analysis using the ONS Longitudinal Study (LS), which tracks individuals and their households over ten year periods through the census. However, the LS sample was too small to examine Pakistanis and Bangladeshis separately, and so was not appropriate for this study. Furthermore, although my exploratory analysis of the LS confirmed the findings of the LFS analysis in relation to economic activity, the ten-year follow-up meant there were countless unobserved transitions in health and economic activity, and was too long a period to observe changes livelihood outcomes in relation to ill-health.
- II. **Mismatch between the individual and household variables.** In the household-level analysis, ethnic group and education data relating to the household reference person were used as a

proxy for the entire household, but this undoubtedly simplifies a much more complex picture of mixed-ethnicity and diverse households.

- III. Mismatch between health status variables and the eligibility criteria for Disability Living Allowance.** To assess eligibility, DLA claimants must self-complete a personal capabilities assessment (PCA), and a claimant may subsequently be examined by a Department for Work and Pensions examining doctor if a decision cannot be made on the basis of the PCA. A person who reports long-term ill-health is not necessarily eligible for DLA, as the eligibility criteria are much more complex and restricting.

Moreover, livelihoods are too complex and intangible to be captured by non-specialist surveys like the LFS. These limitations in the quantitative analysis are overcome by their juxtaposition with the qualitative research, which serves to triangulate and 'thicken' the findings.

Chapter 3: Levels and differentials in long-term ill-health and livelihood outcomes

3.1. Introduction

This chapter uses quantitative data from the Labour Force Survey, a nationally representative survey of private households. First, it examines levels of long-term ill-health among Pakistanis in the UK, and some of the more tangible livelihood outcomes, as a backdrop to understanding the resources and activities that structure the household response to ill-health. Secondly, the chapter analyses the impact of long-term ill-health on the livelihoods of long-term sick Pakistanis and their households, to contextualise the ‘thicker’ ethnographic findings detailed in the later chapters. It examines economic impact not only in terms of individual formal employment, but in terms of the broader concept of livelihoods, with an emphasis on household processes and diverse sources of income. Third, the chapter addresses whether the relationships between long-term ill-health and livelihoods are statistically distinct in Pakistanis compared with other groups. This is an important question given the material and cultural differences between the ethnic groups and the interplay of inclusion and exclusion which may differentiate the impact of ill-health, as I outlined in Chapter 1. It engages with the question of “how, where, why, and under what circumstances” (Archer 2003) (p.20) ethnicity may be important to the consequences of ill-health.

The significance of ethnicity in the livelihoods of Pakistani households may be seen as the exigency of a more encompassing process of material differentiation and class relations. A substantial body of quantitative sociology has shown that Pakistanis and Bangladeshis have poorer qualifications compared with other ethnic groups, a lower distribution in occupational class, are overrepresented in low-skilled and manual sectors, and have a high degree of occupational segregation. They have higher rates of unemployment and economic inactivity than most ethnic groups (Modood and Berthoud 1997; Berthoud 1998; 2003; Simpson, Purdam et al. 2006). Among women, levels of unemployment and inactivity are vastly higher than for men, a complex phenomenon which relates to migration histories, education, skills and household composition as well as culture (Holdsworth and Dale 1997; Dale 2002; Dale, Shaheen et al. 2002; Ahmad, Modood et al. 2003; Lindley, Dale et al. 2004). Pakistanis have higher levels of benefits use than other ethnic groups, but they also have higher levels of unmet need (Platt 2002; Platt 2003b). Analysis of class mobility has also shown that there has been a lesser extent of intergenerational upward movement among Pakistanis than for other ethnic groups, and that educational achievement has been less able to outweigh the inhibitions to upward mobility for

Pakistanis (Strelitz 2004; Platt 2005; Heath and Cheung 2006; Simpson, Purdam et al. 2006). Despite the broad deprivation of Pakistanis in the UK, it is important not to overlook economic heterogeneity. In general, the Kashmiris or Mirpuris were drawn from poorly educated, landowning migratory origins, whereas the Punjabis tended to be better educated and of urban stock, and secured better occupations in the UK, which has had a long-lasting impact on class structures among Pakistanis (Ali, Ellis et al. 1996; Kalra 2000). The shift to self-employment during the 1980s and 1990s and investment in the education of children amplified class distinctions among Pakistanis. Increasingly, survey data suggest a bifurcation in occupational class along the lines of education, with greater proportions of Pakistanis going into professional occupations, but also into unskilled work (Clark and Drinkwater 2007). Young Pakistani males are more likely to enter tertiary education than their White counterparts, but they are also overrepresented among those with low or no qualifications (Modood 2004). High proportions of degree-educated Pakistani women enter paid work once their children reach school age, and they are also likely to be in dual-earner households, whilst unqualified Pakistani women are very likely to be inactive (Dale, Shaheen et al. 2002; Lindley, Dale et al. 2006; Salway 2007a).

There is general agreement that migration histories are the single most important factor in explaining the economic position of Pakistanis in the UK. Pakistani labour migrants were incorporated into the most precarious occupations of moribund industries, and in geographical areas that went on to experience extremely high levels of redundancy and unemployment during the process of industrial restructuring (Green 1997; Modood and Berthoud 1997). However, local economic conditions are not sufficient to explain their economic disadvantage. Within each area and industry, Pakistanis are found to experience higher levels of unemployment than other ethnic groups, despite facing similar local conditions in those areas (Iganski and Payne 1999; Simpson, Purdam et al. 2006). The role of discrimination as a perennial factor excluding Pakistanis from resources such as employment, education, housing and welfare entitlements is therefore likely to be considerable (Green, Connolly et al. 2004; Abrams and Houston 2006).

To date, there has been little exploration of the role of long-term ill-health in the relatively disadvantaged economic position of Pakistanis in the UK. Existing studies have documented disproportionately high levels of economic inactivity among long-term sick Pakistanis (Smith and Twomey 2002; Szczepura, Gumber et al. 2004; Simpson, Purdam et al. 2006) as well as high levels of poverty among carers (Young, Grundy et al. 2006) and disproportionately low use of Incapacity Benefit (IB) among men (Salway, Platt et al. 2007). Analyses of pay have shown that

ethnic pay penalties are much greater than those incurred by long-term ill-health, and that ethnic penalties in pay are found irrespective of health status (Szczepura, Gumber et al. 2004; Salway, Platt et al. 2007). However, seldom has the contribution of cross-cutting socio-demographic factors to these ethnic patterns been considered. This chapter therefore presents novel statistical analyses investigating six dimensions of the circumstances of working-age adults with long-term ill-health among Pakistanis, comparing them with other ethnic groups in the UK:

1. Levels of long-term ill-health among working-age adults.
2. Levels of long-term ill-health among working-age households.
3. Composition of households containing long-term sick working-age adults.
4. Levels of economic activity among long-term sick working-age adults.
5. Economic activity in households containing long-term sick working-age adults.
6. Levels of receipt of DLA among long-term sick working-age adults.

Throughout the chapter I discuss results that are statistically significant at the 5% level, meaning that there is a probability of only 5% (or less) that the observed associations could have arisen by chance if there were no true association in the population.

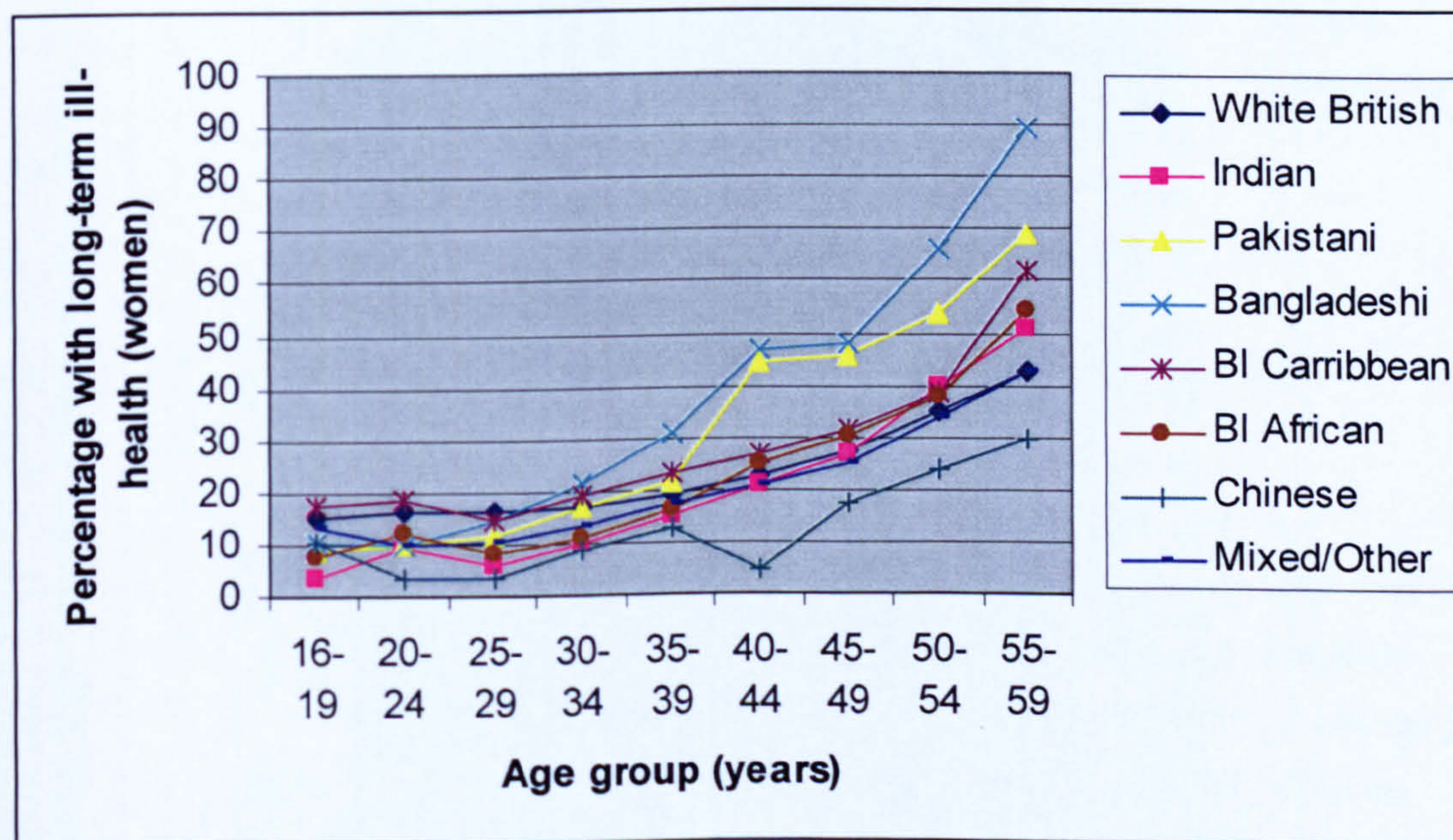
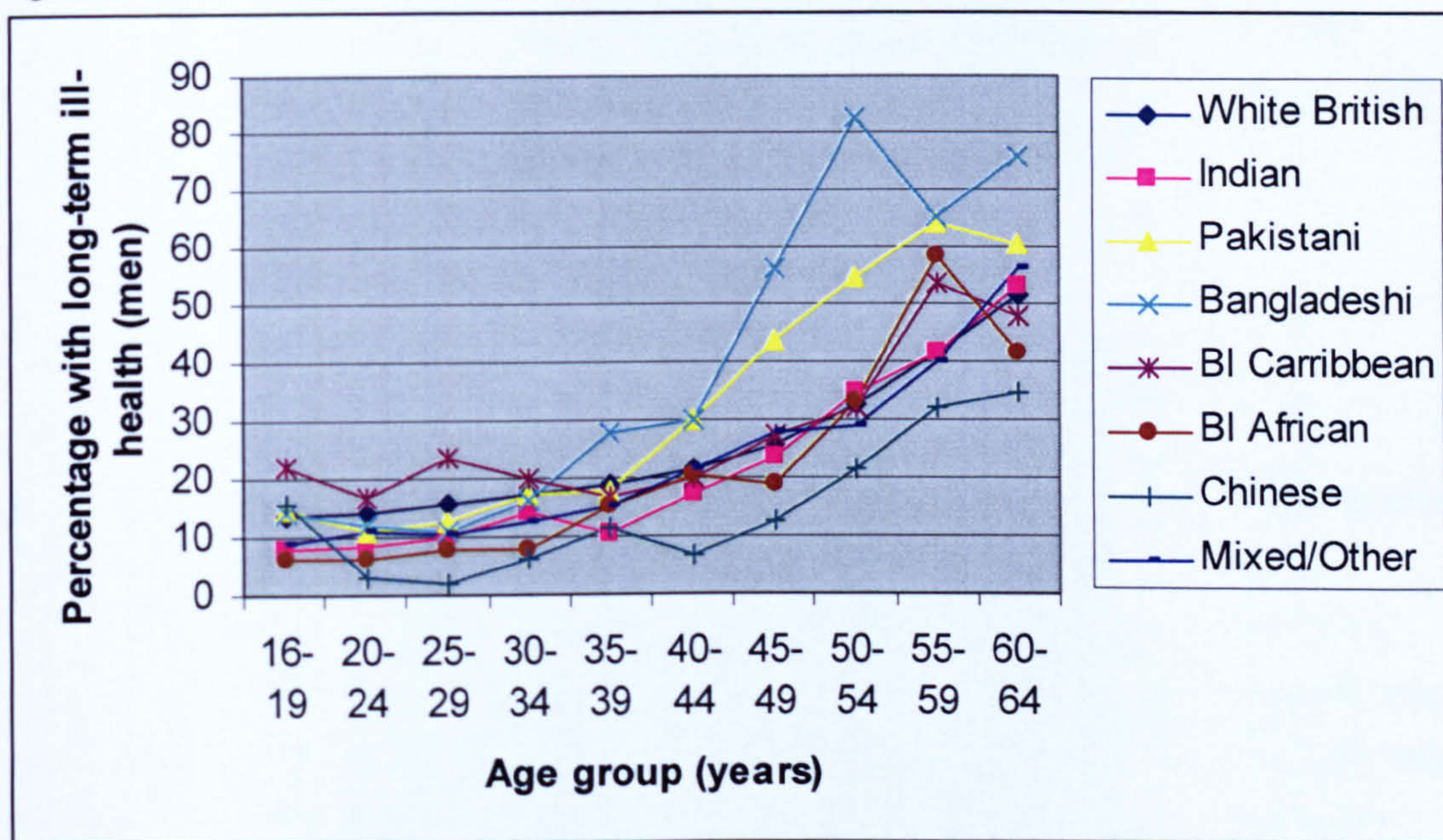
3.2. Results

3.2.1. Levels of long-term ill-health among working-age adults

Twenty five percent of all working-age Pakistanis reported that they had a health problem or disabilities that they expected to last a year or more (henceforth 'long-term ill-health'), and 19% reported long-term ill-health that substantially limited their ability to carry out normal day-to-day activities ('activity limitations'). The overall levels of ill-health are similar to the 25% and 15% in the general population respectively, although the Pakistani population is substantially younger than the general population (see the descriptive statistics in Appendices 1 and 2). Figures 3.1. and 3.2. show the proportions of men and women reporting long-term ill-health and activity limitations by ethnic group and age (p.55). As the graphs indicate, the levels of long-term ill-health begin to diverge between the ethnic groups beyond age 30, and beyond age 40 the Pakistanis and Bangladeshis are much more likely than other people to report long-term ill-health.

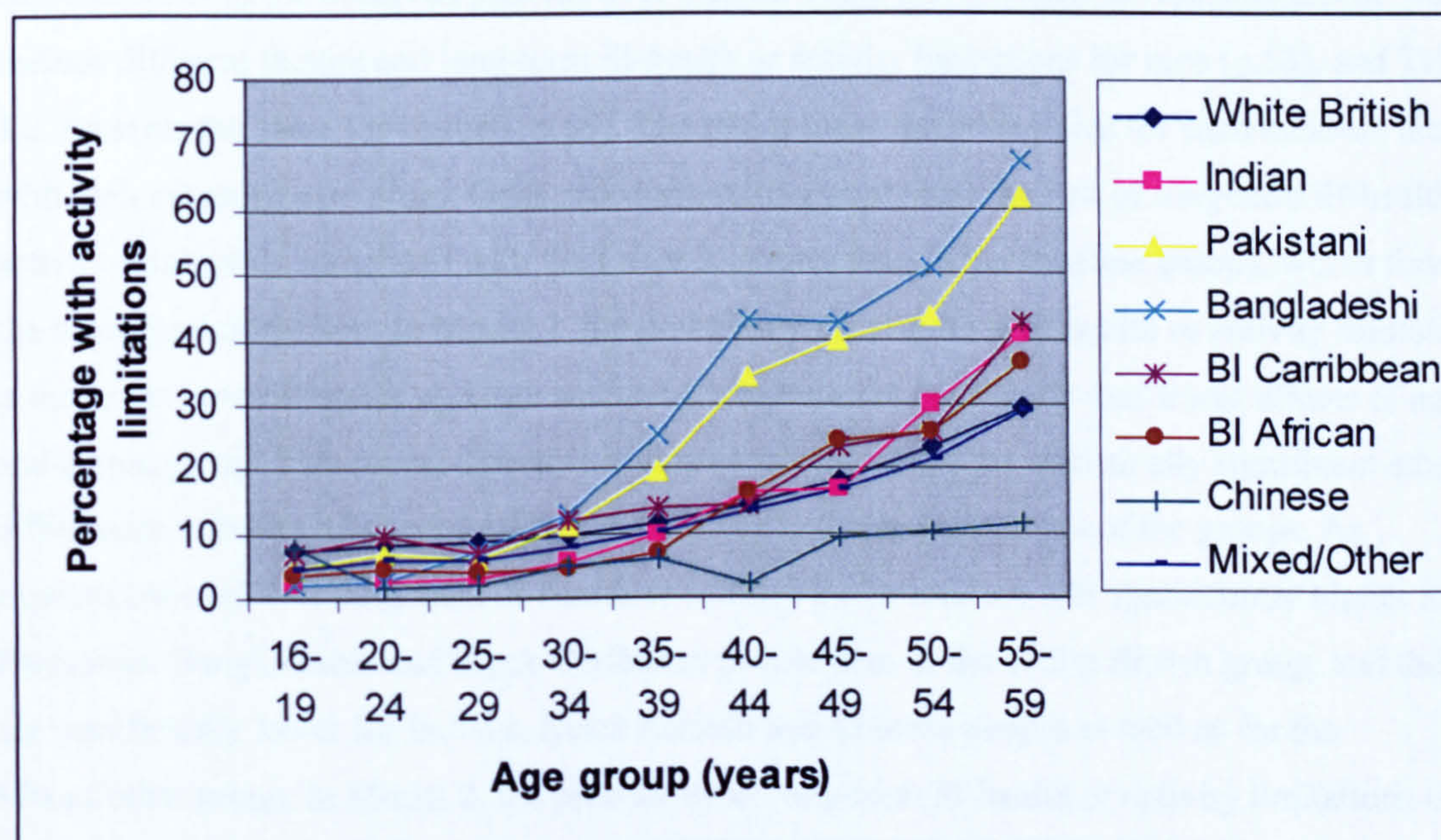
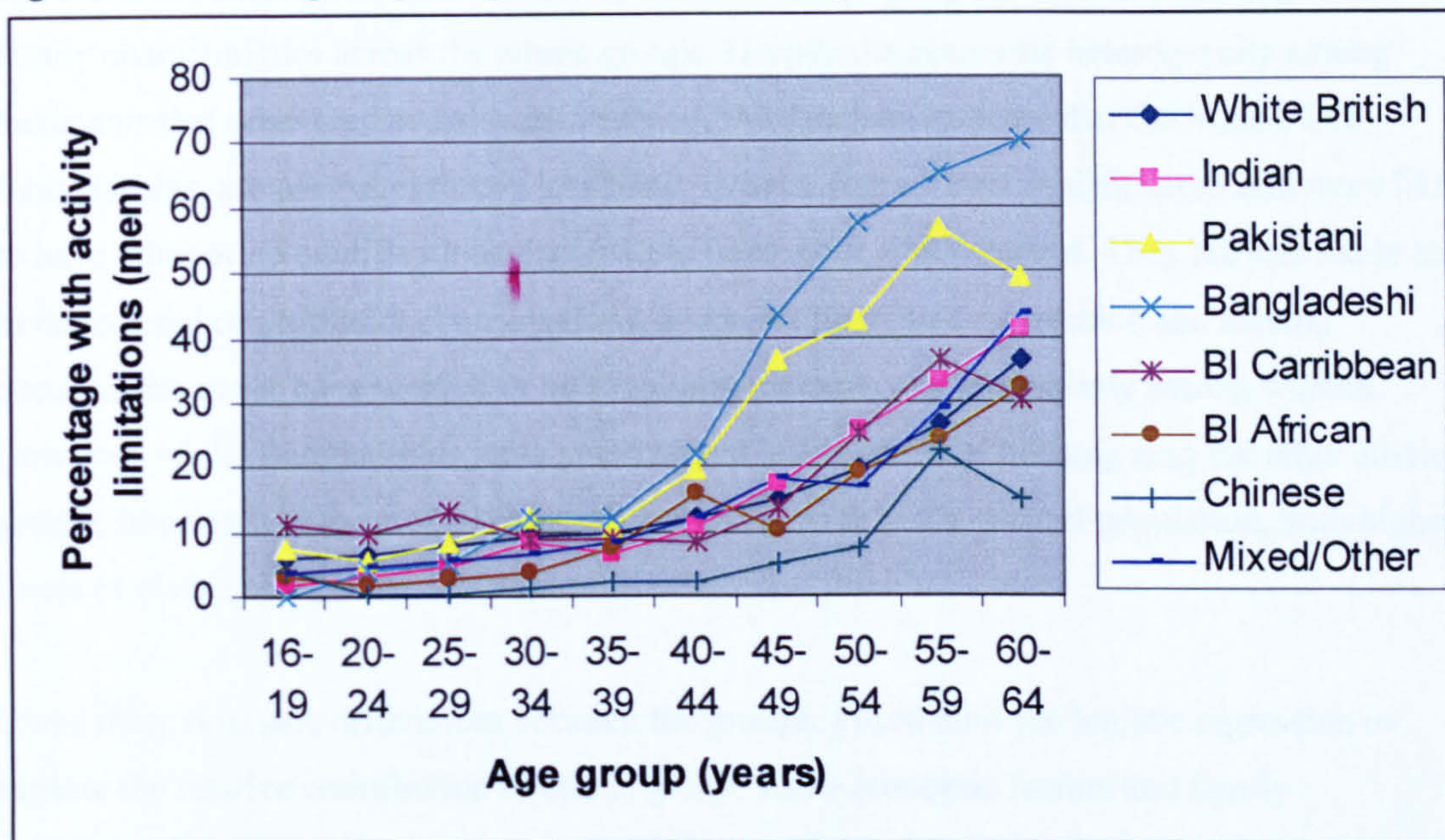
Seventy five percent of Pakistanis with long-term ill-health also reported activity limitations, compared with 60% in the general population. Among the Pakistani adults with long-term ill-health, 42% named one specific health condition, 22% named two specific conditions and 36% named three or more specific health conditions, compared with 51%, 20% and 29% respectively in the general population. These differences are statistically significant below $p < 0.001$ according to a X^2 test ($X^2=227$). The ill-health among Pakistanis is therefore particularly severe.

Figure 3.1.: Percentages reporting long-term ill-health by ethnic group



Data source: LFS 2002-05 (pooled quarters).

Figure 3.2: Percentages reporting activity limitations by ethnic group



Data source: LFS 2002-05 (pooled quarters).

Health-related return migration, in which ill-health prevents migrants from returning to their countries of origin and concentrates ill-health among those who remain in the destination countries, may influence the stark ethnic inequalities in health at older ages (see Evandrou 2000; Nazroo 2006). However, the data here suggest that these ethnic differences in health are substantially related to the relative economic status of Pakistanis and Bangladeshis. Appendices 1

and 2 contain descriptive statistics on educational status, occupational class, housing tenure and family characteristics across the ethnic groups. Despite the economic heterogeneity among Pakistanis that other studies have documented, the data here indicate that Pakistanis, like Bangladeshis, are overwhelmingly less likely to have degree level qualifications and more likely to have other or no qualifications than people from other ethnic groups. They are less likely to be in managerial or professional occupations, and more likely to be in routine and manual occupations, never have worked or be long-term unemployed, particularly among women. However, whilst Bangladeshis have much higher levels of social housing than the other ethnic groups, housing tenure among Pakistanis is more similar to the general population, with higher levels of owner occupation.

Given these dramatic differences between the groups, I used multiple logistic regression to explore the relative contribution of ethnic group, socio-economic factors and family characteristics to the observed patterns of ill-health. Table 3.1. presents the associations between various different factors and long-term ill-health or activity limitations for men (p.58), and Table 3.2. presents the same for women (p.59). The tables show the odds ratios for each measure along with their respective p-values. Odds ratios above one imply that the risk of long-term ill-health or activity limitations associated with the factor is greater than in the baseline groups, which form the basis for comparison. In Model 1, the probability of long-term ill-health or activity limitations is modelled controlling for age, age squared (to capture the potentially non-linear effects of age) and ethnic group. This model therefore indicates whether there are statistically significant ethnic differences in health after controlling for variation in the age structures of the groups. As expected, the odds of long-term ill-health or activity limitations are still significantly higher for Pakistanis, Bangladeshis and Black Caribbean people than in the White British group, and they are significantly lower for Indians, Black African and Chinese people as well as for the Mixed/other group. In Model 2, the probability of long-term ill-health or activity limitations is modelled controlling additionally for socio-economic factors and family characteristics. For the men, we find that the excess odds of long-term ill-health and activity limitations among Pakistanis are much reduced, and for Bangladeshis are completely explained by including these factors. For the women, the excess odds of long-term ill-health or activity limitations among Pakistanis and Bangladeshis are reversed, so that they move below zero. This analysis is not novel, but it serves to confirm existing research showing that a substantial amount of the excess ill-health among Pakistanis can be attributed to their structural disadvantage (see Nazroo 1997; Nazroo 1998; Davey Smith, Chaturvedi et al. 2000; Nazroo 2003).

Table 3.1: Estimates from logistic regression indicating the effects of relevant factors on long-term ill-health and activity limitations among men

	Long-term ill-health				Activity limitations			
	Model 1		Model 2		Model 1		Model 2	
	OR	P-value	OR	P-value	OR	P-value	OR	P-value
<i>Age</i>	0.96	<0.001	1.00	0.668	0.97	0.000	1.01	0.060
<i>Age squared</i>	1.11	<0.001	1.06	<0.001	1.10	0.000	1.05	<0.001
<i>Ethnicity</i>								
White British	1		1		1		1	
Indian	0.81	<0.001	0.82	0.002	1.01	0.866	1.03	0.719
Pakistani	1.33	<0.001	1.16	0.044	1.81	0.000	1.50	<0.001
Bangladeshi	1.44	0.001	1.01	0.928	1.76	0.000	1.02	0.896
Black Caribbean	1.07	0.421	0.81	0.017	1.01	0.935	0.65	<0.001
Black African	0.70	<0.001	0.52	<0.001	0.74	0.018	0.46	<0.001
Chinese	0.44	<0.001	0.44	<0.001	0.31	0.000	0.33	<0.001
Mixed/other	0.88	<0.001	0.80	<0.001	0.98	0.517	0.85	<0.001
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas			1				1	
Level 3 + apprenticeships			1.17	<0.001			1.30	<0.001
Level 2			1.24	<0.001			1.28	<0.001
Level 1 [equivalent to GCSE]			1.29	<0.001			1.42	<0.001
Other			1.26	<0.001			1.42	<0.001
None			1.47	<0.001			1.76	<0.001
<i>NSSEC</i>								
Managerial & professional			1				1	
Intermediate			1.09	<0.001			1.17	<0.001
Routine & manual			1.21	<0.001			1.29	<0.001
Neverworked or long-term unemployed			3.29	<0.001			4.27	<0.001
Full-time student			1.14	0.007			1.05	0.443
<i>Housing</i>								
Owner occupied			1				1	
Rented privately			1.15	<0.001			1.20	<0.001
Social housing			1.94	<0.001			2.27	<0.001
<i>Family characteristics</i>								
Not married or cohabiting			1.23	<0.001			1.27	<0.001
Child(ren) below 5 years			0.94	0.025			0.94	0.099
<i>Quarterly regional unemployment rate</i>			0.98	0.001			1.00	0.998
<i>Region</i>			0.99	<0.001			0.99	<0.001
<i>Quarterly dummies</i>	1.00	0.962	1.00	0.866	1.00	0.995	1.00	0.210
Pseudo R2		0.063		0.075		0.070		0.094
Number of observations		304217		289301		304217		289301

Data source: LFS 2002-5 (pooled quarters).

Table 3.2: Estimates from logistic regression indicating the effects of relevant factors on long-term ill-health and activity limitations among women

	Long-term ill-health				Activity limitations			
	Model 1		Model 2		Model 1		Model 2	
	OR	P-value	OR	P-value	OR	P-value	OR	P-value
<i>Age</i>	0.95	<0.001	0.98	<0.001	0.99	0.013	1.01	0.021
<i>Age squared</i>	1.12	<0.001	1.08	<0.001	1.08	<0.001	1.04	<0.001
<i>Ethnicity</i>								
White British	1		1		1		1	
Indian	0.79	<0.001	0.76	<0.001	0.91	0.175	0.84	0.027
Pakistani	1.31	<0.001	0.86	0.044	1.75	<0.001	1.00	0.971
Bangladeshi	1.53	<0.001	0.83	0.129	1.83	<0.001	0.77	0.054
Black Caribbean	1.26	0.001	1.08	0.341	1.21	0.021	0.99	0.942
Black African	0.85	0.043	0.56	<0.001	0.80	0.030	0.45	<0.001
Chinese	0.43	<0.001	0.42	<0.001	0.37	<0.001	0.38	<0.001
Mixed/other	0.85	<0.001	0.80	<0.001	0.86	<0.001	0.80	<0.001
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas			1				1	
Level 3 + apprenticeships			1.08	0.004			1.15	<0.001
Level 2			1.11	<0.001			1.12	0.001
Level 1 [equivalent to GCSE]			1.15	<0.001			1.18	<0.001
Other			1.13	<0.001			1.17	<0.001
None			1.29	<0.001			1.46	<0.001
<i>NSSEC</i>								
Managerial & professional			1				1	
Intermediate			1.01	0.821			1.01	0.660
Routine & manual			1.19	<0.001			1.28	<0.001
Neverworked or long-term unemployed			2.38	<0.001			3.03	<0.001
Full-time student			1.08	0.085			1.09	0.146
<i>Housing</i>								
Owner occupied			1				1	
Rented privately			1.19	<0.001			1.20	<0.001
Social housing			1.88	<0.001			2.08	<0.001
<i>Family characteristics</i>								
Not married or cohabiting			1.27	<0.001			1.31	<0.001
Child(ren) below 5 years			0.81	<0.001			0.77	<0.001
<i>Quarterly regional unemployment rate</i>			0.98	<0.001			0.99	0.158
<i>Region</i>			1.00	0.004			0.99	<0.001
<i>Quarterly dummies</i>	1.00	0.906	1.00	0.409	1.00	0.120	1.00	0.143
Pseudo R2		0.044		0.057		0.047		0.070
Number of observations		302910		276508		302910		276508

Data source: LFS 2002-5 (pooled quarters).

3.2.2. Levels of long-term ill-health among working-age households

This analysis is restricted to the subset of households containing working-age adults, which I refer to as 'households' for the sake of simplicity. Similarly, the analysis concentrates on the health of working-age household members, who I refer to as 'adults', rather than children or people above retirement age. This concentrates the analysis on the economic impact of the ill-health of the household members who are the most productive.

Forty eight percent of Pakistani households contained at least one adult reporting long-term ill-health, and 39% contained at least one adult reporting activity limitations. This compares with 41% and 28% of households in the general population. The prevalence of ill-health in working-age Pakistani households is therefore particularly high.

Although seldom remarked upon in the literature, the results also demonstrate a 'clustering' (Glaser, Murphy et al. 1997) of long-term ill-health in households. In Pakistani households, as in the general population, adults reporting long-term ill-health are more likely than those without ill-health, to live in households containing other long-term sick adults. The same is also true for activity limitations. However, as Table 3.3. shows, Pakistani and Bangladeshi households are more likely than others to contain adult(s) reporting long-term ill-health or activity limitations (p.61). The ethnic differences are statistically significant at below $p < 0.001$ according to X^2 tests ($X^2 = 629$ for household members reporting long-term ill-health and $X^2 = 443$ for activity limitations). Looking in more detail, we can see that the greater prevalence of long-term ill-health or activity limitations in Pakistani and Bangladeshi households is due, in particular, to having *multiple* adults reporting these problems. Of all the ethnic groups, the clustering of long-term ill-health is therefore greatest in the Pakistani and Bangladeshi households.

This could be driven by the size and composition of Pakistani and Bangladeshi households, which are larger than average and more likely to have a complex (i.e. non-nuclear) family structure. To explore this further, I carried out multiple regression analyses to model the presence of long-term ill-health or activity limitations in working-age households, which are presented in Appendix 4. As Appendix 4 shows, the raised odds of Pakistani and Bangladeshi households containing working-age household members with long-term ill-health or activity limitations do not reduce after controlling for household size and composition, which implies that they are mostly driven by the higher levels of long-term ill-health among Pakistanis and Bangladeshis.

Table 3.3: Percentages of households with one or more working-age member(s) reporting long-term ill-health or activity limitations, by ethnic group

	Percentage of households reporting working-age members with long-term ill-health			Percentage of households reporting working-age members with activity limitations			Number of households
	One or more long-term sick adult	No. of long-term sick adults	Multiple sick adults	One or more activity limited adult	No. of activity limited adults	Multiple sick adults	
Pakistani	48%	33%	15%	39%	29%	10%	1,955
Overall	41%	32%	8%	28%	24%	4%	234,240
White British	42%	33%	9%	28%	24%	4%	200,379
Indian	37%	27%	10%	28%	22%	6%	3,436
Bangladeshi	46%	32%	14%	35%	26%	9%	725
B1 Caribbean	36%	31%	5%	23%	21%	2%	2,583
B1 African	26%	23%	3%	17%	15%	2%	2,269
Chinese	20%	17%	4%	11%	9%	2%	781
Mixed/Other	37%	30%	7%	26%	22%	4%	22,112

Note: Households were restricted to those containing one or more persons of working-age. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person.

Data source: HLF5 2002-4.

3.2.3. Composition of households containing long-term sick working-age adults

Overall 8% of Pakistani households containing working-age long-term sick adults are single-person households, but 92% contain multiple persons. The vast majority of long-term sick Pakistanis are therefore living with other people. Most commonly they live in couples with dependent children (37%), or in complex, multiple family households (22%). As Table 3.4. shows (p.63), the composition of Pakistani households containing working-age long-term sick adults is markedly different from average in the UK. Like their Indian, Bangladeshi and Chinese counterparts, Pakistani households are much less likely to consist of single persons compared with the White British, Black Caribbean or Black African households. Like the Bangladeshi, Black Caribbean and Black African households, Pakistani households are slightly more likely to be lone parent households with dependent children than the average – a type of household that potentially presents heavy demands on single adult as they have to attend not only to the needs of dependent children, but also to their own health needs (Casebourne and Britton 2004). Along with the Indian and Bangladeshi households, Pakistani households are much more likely than average to contain dependent children and multiple families. Long-term sick Pakistani adults are therefore highly likely to be living with other household members present. On the one hand, the other household members could be providing them with assistance, but they might equally present additional demands for care, as for people who are living in households containing dependent children, elderly people or other long-term sick adults.

Looking in more detail at the membership of households containing adults with long-term ill-health, in Table 3.5. we see that 66% of Pakistani households containing working-age long-term sick adults contain dependent children aged 0-15 years, which is strikingly higher than in the other ethnic minority groups, aside from the Bangladeshis (p.64). Twelve percent of Pakistani households contain one or more elderly person(s), who are likely to place demands for care on the person with long-term ill-health rather than primarily be able to provide them with help with their own health problems. Furthermore, the statistics are very likely to underestimate the true extent of dependency as they are based on a definition of households as co-residential rather than economic units, failing to identify dependent children, elderly people or long-term sick adults in other nearby households, for whom individuals may also be providing care.

Table 3.4: Composition of households containing one or more person(s) of working-age with long-term ill-health by ethnic group.

	Single person	Couple without children	Couple with dependent children	Couple with non-dependent children	Lone parent with dependent children	Lone parent with non-dependent children	Complex (multiple family) households	Number of households
Pakistani	6%	7%	37%	6%	10%	2%	22%	936
Overall	17%	26%	27%	10%	8%	4%	7%	95,796
White British	17%	29%	26%	11%	7%	4%	6%	83,437
Indian	7%	15%	34%	12%	5%	4%	22%	1,270
Bangladeshi	3%	4%	52%	4%	11%	2%	24%	325
BI Caribbean	28%	11%	18%	6%	23%	8%	7%	936
BI African	24%	8%	21%	1%	27%	5%	13%	593
Chinese	13%	16%	29%	17%	9%	2%	16%	158
Mixed/Other	19%	21%	28%	10%	9%	4%	9%	8,141

Note: Households were restricted to those containing one or more persons of working-age. Complex households consisted of multiple-family households (including those in which one of the families consists of a single person) and couple or lone parent families in which people other than children are also present. Dependent children were classified as those below 19 years. Ethnic group was assigned on the basis of the ethnicity of the household reference person. Data source: HLFS 2002-4.

Table 3.5: Presence of dependent children and elderly people in households containing one or more person(s) of working-age with long-term ill-health by ethnic group

	Household containing one or more child(ren) aged 0-15 years	Household containing one or more elderly persons	Number of households
Pakistani	66%	12%	936
Overall	32%	11%	95,796
White British	31%	11%	83,437
Indian	44%	15%	1,270
Bangladeshi	78%	19%	325
Black Caribbean	42%	7%	936
Black African	49%	4%	593
Chinese	37%	8%	158
Mixed/Other	35%	11%	8,141

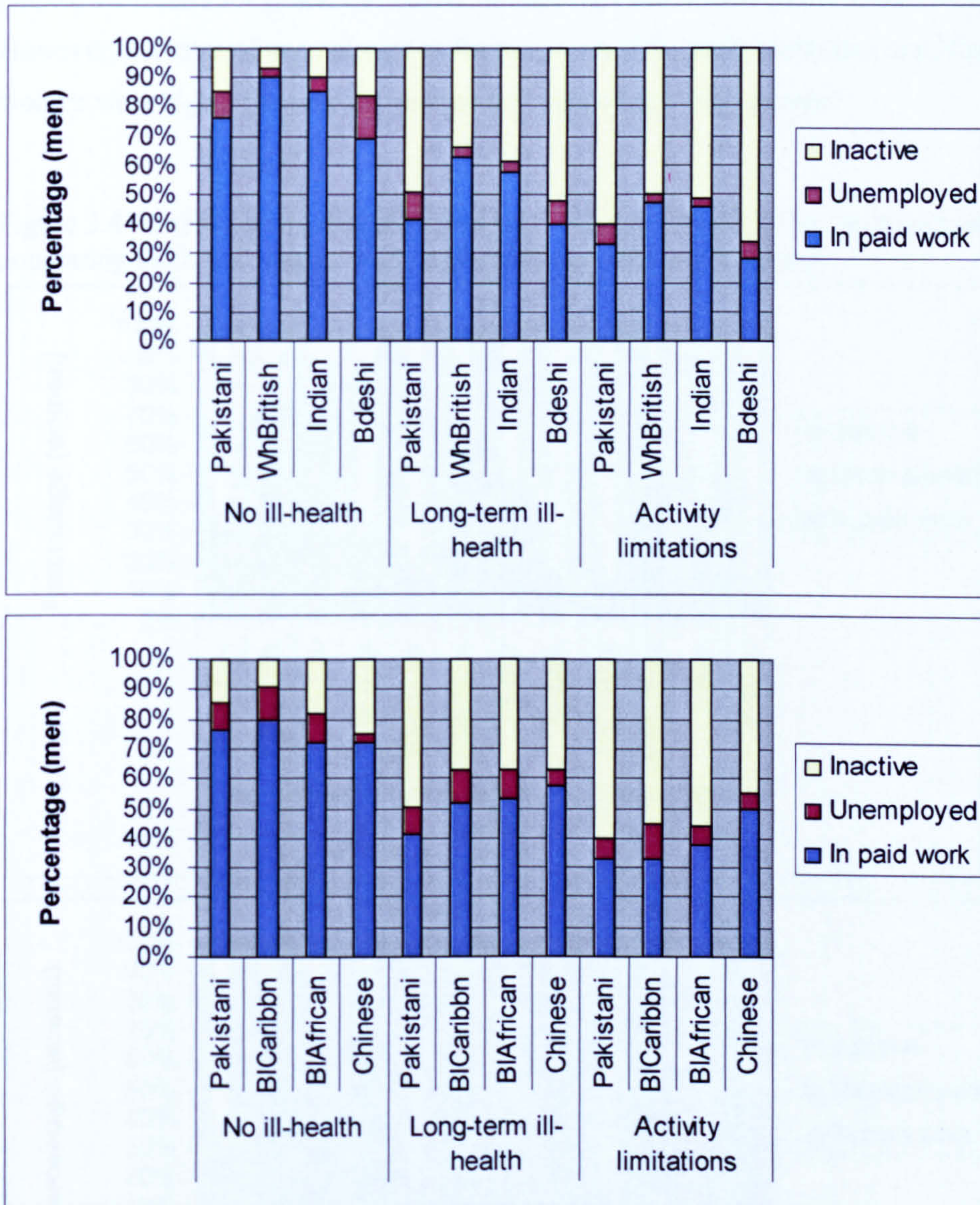
Note: Households were restricted to those containing one or more person of working-age. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person.
Data source: HLFS 2002-4.

3.2.4. Levels of economic activity among long-term sick working-age adults

Across the board, we find that employment rates are lower among those reporting long-term ill-health and lower still among those reporting activity limitations. Just 42% of long-term sick working-age Pakistani men and 33% of those with activity limitations are in employment, compared with 76% among those reporting no health problems. In the general population, 61% of long-term sick men, 46% of men with activity limitations and 89% of men reporting no health problems are in employment. Rates of employment among Pakistani men are therefore relatively low in each of the groups defined by health. Half the long-term sick Pakistani men are inactive, although a further 9% are unemployed. This implies that long-term ill-health does not translate into inactivity for all, and that some are still actively looking for work.

Figure 3.3. illustrates the rates of employment, unemployment and economic inactivity by health and ethnic group for men (p.66). The differences across ethnic groups are notable. White British men have the highest employment rates and the lowest rates of worklessness in each of the groups defined by health status. The Pakistani men stand out for having particularly high levels of inactivity across health status groups, in which respect they are similar to the Bangladeshi men. The Pakistani and Bangladeshi men differ in turn from their Black Caribbean counterparts, who have higher rates of unemployment pending on long-term ill-health as well as higher rates of inactivity, which suggests that more of them are still actively looking for work. Among the ethnic minority men, the Chinese are distinguished by their relatively high employment rates compared to the other groups. Overall, therefore, it looks as if long-term sick Pakistani men are one of the groups with the lowest chances of being in employment. The patterns are quite consistent with the well-documented employment disadvantage among Pakistanis that I described at the beginning of the chapter, even without the additional consideration of ill-health.

Figure 3.3.: Employment, unemployment and economic inactivity by health status, comparing Pakistani men with counterparts in other ethnic groups

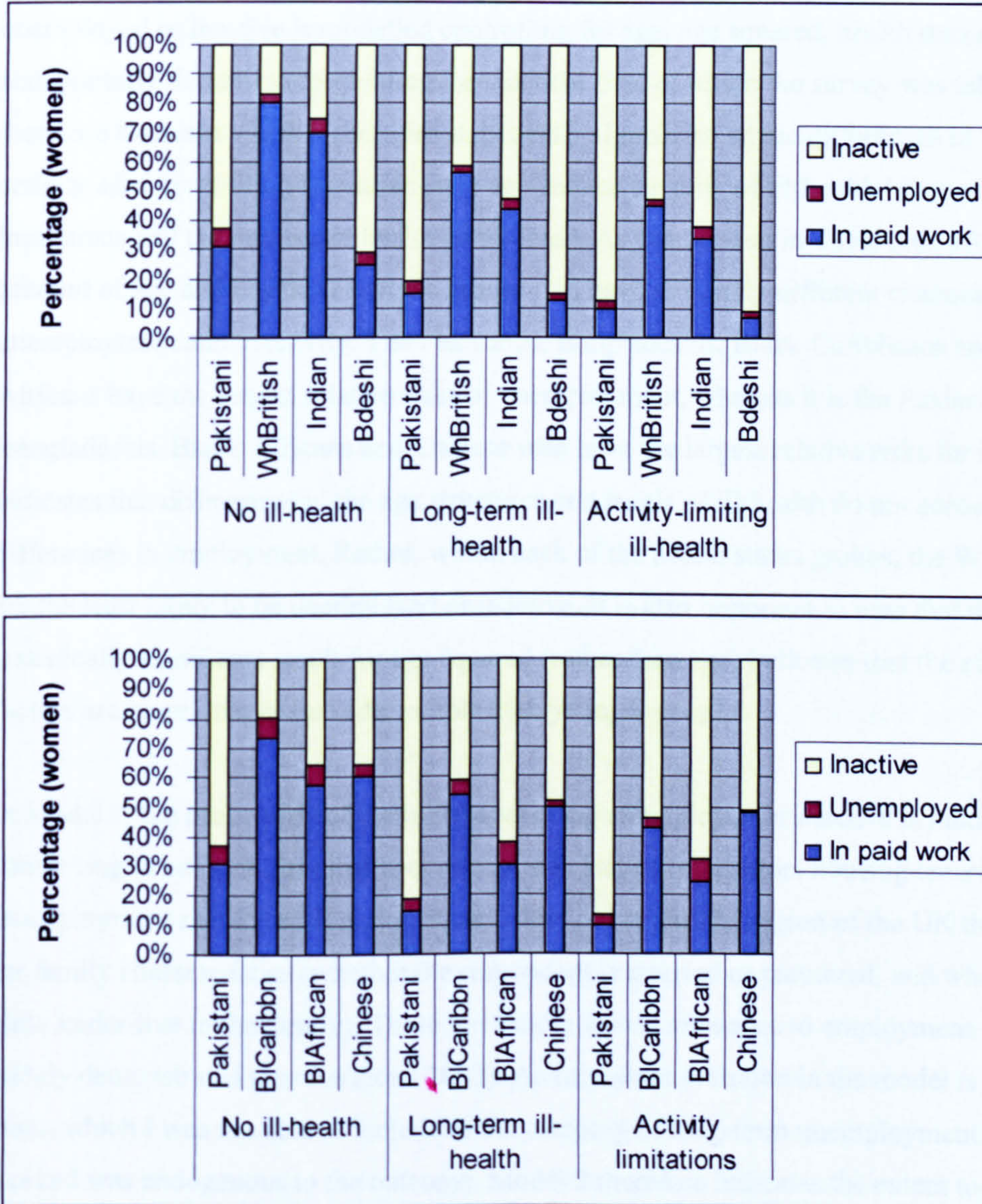


Data source: LFS 2002-05 (pooled quarters).

Looking at the results for the women, we find similar patterns, although as expected, the inactivity rates are much higher and the unemployment rates are lower than men. Just 31% of the Pakistani women reporting no ill-health were in employment, going down to 15% for those with long-term ill-health and 10% for those with activity limitations. The corresponding figures for the general population were 78%, 54% and 43% respectively. Figure 3.4. (p.67) shows the rates of employment, unemployment and economic inactivity by health and ethnic group for women and illustrates that, as for the men, the White British women have the highest employment rates and

the lowest rates of unemployment and inactivity across all the groups defined by health. The employment rates for Black Caribbean women high and similar to the White British women. However, the rates of unemployment for long-term sick Black Caribbean and Black African women were higher than for the women from the other ethnic groups.

Figure 3.4: Employment, unemployment and economic inactivity by health status, comparing Pakistani women with counterparts in other ethnic groups



Data source: LFS 2002-05 (pooled quarters).

I used multinomial logistic regression to explore the relative contribution of health status, ethnic group and other relevant factors to these patterns of employment. Here, I summarize the main results for men and women, focussing on the role of long-term ill-health and activity limitations in the complex patterns of economic activity mapped out in the models.

Table 3.6. presents the associations between various different factors and unemployment or economic inactivity for men (p.70). In Model 1, the probability of the respondent being unemployed or inactive is modelled controlling for age, age squared, health status, ethnic group and quarterly dummies representing the calendar time at which the survey was taken. This model therefore indicates whether there are statistically significant ethnic differences in economic activity after controlling for variation in age and the severity of ill-health (the presence of activity limitations and the number of health conditions). As can be seen in Table 3.6., after taking account of age and health, the ethnic groups still have strikingly different chances of unemployment and inactivity. The Pakistanis, Bangladeshis, Black Caribbeans and Black Africans have the largest relative risks of unemployment, whereas it is the Pakistanis, Bangladeshis, Black Africans and Chinese who have the largest relative risks for inactivity. This indicates that differences in the age structures and levels of ill-health do not account for the ethnic differences in employment. Rather, within each of the health status groups, the White British men are the least likely to be unemployed or inactive. It is also important to note that the strong statistically significant result for age squared (rather than age) indicates that the effects of all the factors are more intense for older people than younger people.

In Model 2, the probability of the individual being unemployed or inactive is modelled controlling in addition for other socio-economic factors (education, housing tenure, the unemployment rate for each region at each time point, and the region of the UK they live in) and for family characteristics (whether the respondent is married or partnered, and whether there is a child under five in the family). These are factors whose relevance to employment status has been widely demonstrated (see Berthoud 2003). An important omission in the model is occupational class, which I was not able to include as the category of long-term unemployment or never having worked was endogenous to the outcome. Model 2 therefore indicates the extent to which the ethnic differences in economic activity can be attributed to differences in socio-economic and familial factors between the groups. The inclusion of the additional variables generally decreases the size of the relative risks for age, ill-health and the ethnic minority groups, suggesting that some part of the observed associations with economic activity operated via socio-economic and

familial factors which were differentially distributed between the groups. Interestingly however, the higher chances of unemployment and inactivity of Pakistani men were not explained by the inclusion of the socio-economic factors and family characteristics. Re-running the regressions separately for each of the ethnic groups suggests that this may be due to the higher levels of owner occupation among workless Pakistanis and the lesser numbers of workless Pakistanis with no qualifications (see Appendix 1 for the distribution of these variables by ethnic group).

The comparable results for women are shown in Table 3.7. (p.71). The results were very similar to those for the men, confirming that ill-health also has a strong association with economic activity for women. However, the chances of worklessness for Pakistani and Bangladeshi women were of an order of magnitude higher than for the women from the other ethnic groups, and vastly higher than for the Pakistani and Bangladeshi men. The particularly high relative risk of unemployment for Pakistani women is also worthy of note, as it implies that Pakistani women are more likely than other women to be still actively looking for paid employment, despite the barriers they face to finding it. Interestingly, the relative risks of inactivity associated with having activity limitations were smaller for women than for men. This finding was confirmed by examining the evidence for interactions between sex and health status using Wald tests and the likelihood ratio test. With a probability of less than $p < 0.001$, the tests rejected the hypothesis that the associations between health status and economic activity were the same between men and women. The relatively stronger association between health status and economic activity among men suggests that factors other than health status are more salient influences on economic inactivity among women. Potentially, these might include the male breadwinner ideology, family building patterns and care responsibilities, which are not captured by the LFS.

Besides these key findings, the other main differences between the models for men and women are the relative importance of familial factors. Being single has a stronger association with worklessness for men than for the women, controlling simultaneously for the presence of young children. This is because married/cohabiting men are more likely to be in employment than married/cohabiting women, whether they have children or not, whereas single childless men and women actually have very similar employment rates (see Berthoud 2003). Second, for women, the association between having young children and worklessness is much greater than for the men, as would be expected. The results therefore support the assumption that the processes that associate long-term ill-health with economic activity would be gendered.

Table 3.6: Estimates from multinomial logistic regression indicating the effects of relevant factors on employment, unemployment and economic inactivity among men

	Model 1				Model 2			
	Unemployed		Inactive		Unemployed		Inactive	
	RR	P-value	RR	P-value	RR	P-value	RR	P-value
<i>Age</i>	0.81	<0.001	0.68	<0.001	0.86	<0.001	0.70	<0.001
<i>Age squared</i>	1.24	<0.001	1.62	<0.001	1.19	<0.001	1.59	<0.001
<i>Health factors</i>								
Long-term ill-health	1.35	<0.001	1.24	<0.001	1.19	<0.001	1.15	<0.001
Activity limitations	1.35	<0.001	5.39	<0.001	1.15	0.007	4.81	<0.001
Number of health conditions	1.28	<0.001	1.63	<0.001	1.19	<0.001	1.54	<0.001
<i>Ethnicity</i>								
White British	1		1		1		1	
Indian	1.30	0.005	1.63	<0.001	1.41	<0.001	1.80	<0.001
Pakistani	2.56	<0.001	2.61	<0.001	2.83	<0.001	2.82	<0.001
Bangladeshi	4.29	<0.001	3.46	<0.001	1.97	<0.001	1.99	<0.001
Black Caribbean	3.67	<0.001	1.85	<0.001	1.84	<0.001	1.15	0.237
Black African	3.55	<0.001	3.92	<0.001	1.63	<0.001	2.15	<0.001
Chinese	1.12	0.602	4.34	<0.001	0.91	0.661	3.55	<0.001
Mixed/other	1.83	<0.001	1.93	<0.001	1.37	<0.001	1.60	<0.001
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas					1		1	
Level 3 + apprenticeships					0.94	0.172	1.07	0.027
Level 2					1.11	0.037	0.89	0.007
Level 1 [equivalent to GCSE]					1.36	<0.001	0.93	0.061
Other					1.08	0.136	0.91	0.029
None					1.83	<0.001	1.77	<0.001
<i>Housing</i>								
Owner occupied					1		1	
Rented privately					1.90	<0.001	2.12	<0.001
Social housing					4.40	<0.001	3.48	<0.001
<i>Family characteristics</i>								
Not married or cohabiting					2.54	<0.001	2.21	<0.001
Child(ren) below 5 years					1.10	0.04	1.11	0.008
<i>Quarterly regional unemployment rate</i>								
Region					0.99	0.009	0.98	<0.001
<i>Quarterly dummies</i>	0.98	<0.001	1.00	0.865	0.99	<0.001	1.00	0.143
Pseudo R2				0.2187				0.2717
Number of observations				304217				302114

Data source: LFS 2002-5 (pooled quarters).

Table 3.7: Estimates from multinomial logistic regression indicating the effects of relevant factors on employment, unemployment and economic inactivity among women

	Model 1				Model 2			
	Unemployed		Inactive		Unemployed		Inactive	
	RR	P-value	RR	P-value	RR	P-value	RR	P-value
<i>Age</i>	0.86	<0.001	0.88	<0.001	0.88	<0.001	0.85	<0.001
<i>Age squared</i>	1.15	<0.001	1.17	<0.001	1.14	<0.001	1.24	<0.001
<i>Health factors</i>								
Long-term ill-health	1.31	<0.001	1.10	<0.001	1.17	0.001	1.05	0.09
Activity limitations	1.25	<0.001	2.78	<0.001	1.14	0.03	2.65	<0.001
Number of health conditions	1.25	<0.001	1.46	<0.001	1.18	0	1.41	<0.001
<i>Ethnicity</i>								
White British	1		1		1		1	
Indian	2.00	<0.001	1.63	<0.001	2.24	<0.001	1.78	<0.001
Pakistani	4.91	<0.001	8.34	<0.001	5.08	<0.001	7.47	<0.001
Bangladeshi	3.84	<0.001	11.73	<0.001	2.33	0.001	5.94	<0.001
Black Caribbean	2.51	<0.001	1.20	0.013	1.37	0.009	0.87	0.075
Black African	3.81	<0.001	3.04	<0.001	1.82	<0.001	1.75	<0.001
Chinese	2.03	<0.001	2.60	<0.001	1.88	0.001	3.04	<0.001
Mixed/other	1.91	<0.001	1.71	<0.001	1.55	<0.001	1.57	<0.001
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas					1		1	
Level 3 + apprenticeships					1.13	0.014	1.72	<0.001
Level 2					1.26	<0.001	1.48	<0.001
Level 1 [equivalent to GCSE]					1.72	<0.001	1.96	<0.001
Other					1.51	<0.001	1.86	<0.001
None					1.92	<0.001	4.03	<0.001
<i>Housing</i>								
Owner occupied					1		1	
Rented privately					2.30	<0.001	1.98	<0.001
Social housing					3.63	<0.001	2.93	<0.001
<i>Family characteristics</i>								
Not married or cohabiting					1.65	<0.001	1.07	<0.001
Child(ren) below 5 years					1.49	<0.001	4.65	<0.001
<i>Quarterly regional unemployment rate</i>								
					1.06	<0.001	1.03	<0.001
<i>Region</i>								
					1.00	0.983	1.00	0.005
<i>Quarterly dummies</i>	0.99	0.008	0.99	<0.001	0.99	0.102	1.00	0.374
Pseudo R2				0.0933				0.1879
Number of observations				302910				301140

Data source: LFS 2002-5 (pooled quarters).

3.2.4.1. Differential associations between long-term ill-health and economic activity

To explore whether there might be differentials in the associations between long-term ill-health on employment according to social factors such as ethnic group, education and housing tenure, I tested for interaction effects in the multivariate regression models. Chapter 2 contains a full discussion of the methods used to test for interaction effects.

The investigations around interactions for ethnic group provided no clear evidence of differences in the associations between health status and economic activity across the different ethnic groups. Although likelihood ratio tests carried out on the un-clustered data indicated that the inclusion of interaction terms between ethnic group and long-term ill-health or activity limitations improved the models of economic activity for men and women with a probability of $p < 0.01$, none of the Wald statistics for the individual interaction parameters were much different from 1 or statistically significant; nor did the dummy interaction variables reveal any clear, visible or systematic patterns in the data. Kirkwood and Sterne warn against searching exhaustively for interactions, given the low power of the tests and the potential for chance effects. If weak interactions are found to be present, but no systematic patterns are discernable, then they are “probably of little intrinsic interest”, and the overall pooled estimate of the effect for the factor is acceptable as an approximation to the truth (Kirkwood and Sterne 2003) (p.466). This finding implies that the relative impact of long-term ill-health on employment is similar across the ethnic groups. That is to say that the impact of long-term ill-health on employment is on average no more and no less for, for example, a Pakistani person than for a White British person after accounting for the ethnic differences in age, the severity of the health problems, and the socio-economic factors and family characteristics that are included in the models.

However, the investigations did indicate interaction effects in the associations between health and economic activity across the groups defined by education and housing tenure. The interactions with inactivity were stronger and clearer than those for unemployment. In relation to education, the interactions between long-term ill-health (or activity limitations) and education significantly improved the likelihood of the models for economic activity, with probabilities of less than 0.001, for both men and women. The chances of worklessness pending on ill-health is disproportionately high for people who were poorly qualified, particularly for people who have level 1 qualifications (equivalent to GCSE) or no qualifications at all. The results show an almost perfect step-by-step increase in the odds ratios of the interaction terms with decreasing levels of qualifications. This

relationship is shown in Table 3.8. (p.74), which shows the interaction between activity limitations and worklessness to provide a simplified example. As the table shows, the odds of worklessness for people with no qualifications are much greater than would be expected.

In relation to the interactions with housing tenure, the likelihood ratio tests indicated that the interactions between housing tenure and health status also significantly improve the model ($p < 0.001$). The association between long-term ill-health and economic activity is greater for people who are living in local authority or housing association properties compared with people who are privately renting or who own their own properties. The interaction effects with long-term ill-health are illustrated in Table 3.9. (p.75).

Table 3.8: Estimates from logistic regression indicating interaction effects between activity limitations and education in modelling worklessness

	Men		Women	
	OR	P-value	OR	P-value
<i>Age</i>	0.73	<0.001	0.85	<0.001
<i>Age squared</i>	1.50	<0.001	1.23	<0.001
<i>Health factors</i>				
Long-term ill-health	1.13	<0.001	1.06	<0.001
Number of health conditions	1.50	<0.001	1.40	<0.001
<i>Interaction between activity limitations and education</i>				
No activity limitations X Degree + higher level diplomas	1		1	
No activity limitations X Level 3 + apprenticeships	0.99	0.696	1.68	<0.001
No activity limitations X Level 2	0.90	0.006	1.42	<0.001
No activity limitations X Level 1	0.88	0.001	1.88	<0.001
No activity limitations X Other qualifications	0.90	0.006	1.77	<0.001
No activity limitations X No qualifications	1.34	<0.001	3.32	<0.001
Activity limitations X Degree + higher level diplomas	2.33	<0.001	2.14	<0.001
Activity limitations X Level 3 + apprenticeships	3.08	<0.001	2.89	<0.001
Activity limitations X Level 2	2.79	<0.001	3.32	<0.001
Activity limitations X Level 1	4.53	<0.001	4.57	<0.001
Activity limitations X Other qualifications	2.98	<0.001	4.14	<0.001
Activity limitations X No qualifications	8.37	<0.001	11.58	<0.001
<i>Ethnicity</i>				
White British	1		1	
Indian	1.65	<0.001	1.84	<0.001
Pakistani	2.82	<0.001	7.17	<0.001
Bangladeshi	2.06	<0.001	5.45	<0.001
Black Caribbean	1.47	<0.001	0.94	0.452
Black African	1.97	<0.001	1.77	<0.001
Chinese	2.56	<0.001	2.87	<0.001
Mixed/other	1.55	<0.001	1.57	<0.001
<i>Housing</i>				
Owner occupied	1		1	
Privately rented	2.04	<0.001	2.02	<0.001
Social housing	3.78	<0.001	3.02	<0.001
<i>Family characteristics</i>				
Not married or cohabiting	2.27	<0.001	1.13	<0.001
Child(ren) below 4 years in family	1.14	<0.001	4.07	<0.001
<i>Quarterly regional unemployment rate</i>	1.08	<0.001	1.03	<0.001
<i>Region</i>	0.98	<0.001	1.00	0.011
<i>Quarterly dummies</i>	1.00	0.693	1.00	0.234
Pseudo R2		0.29		0.2
Number of observations		302114		301140

Data source: LFS 2002-5 (pooled quarters).

Table 3.9: Estimates from logistic regression indicating interaction effects between activity limitations and housing tenure in modelling worklessness

	Men		Women	
	OR	P-value	OR	P-value
<i>Age</i>	0.73	<0.001	0.85	<0.001
<i>Age squared</i>	1.50	<0.001	1.24	<0.001
<i>Health factors</i>				
Long-term ill-health	1.12	<0.001	1.06	<0.001
Number of health conditions	1.51	<0.001	1.40	<0.001
<i>Interaction between activity limitations and housing</i>				
No activity limitations X Owner occupied	1		1	
No activity limitations X Privately rented	1.97	<0.001	2.04	<0.001
No activity limitations X Social housing	3.11	<0.001	2.85	<0.001
Activity limitations X Owner occupied	3.15	<0.001	2.33	<0.001
Activity limitations X Privately rented	7.31	<0.001	4.42	<0.001
Activity limitations X Social housing	18.45	<0.001	8.39	<0.001
<i>Ethnicity</i>				
White British	1		1	
Indian	1.67	<0.001	1.84	<0.001
Pakistani	2.82	<0.001	7.11	<0.001
Bangladeshi	2.12	<0.001	5.43	<0.001
Black Caribbean	1.49	<0.001	0.95	0.495
Black African	2.11	<0.001	1.79	<0.001
Chinese	2.61	<0.001	2.86	<0.001
Mixed/Other	1.55	<0.001	1.57	<0.001
<i>Education</i>				
Degree + higher level diplomas	1		1	
Level 3 + apprenticeships	1.04	0.147	1.63	<0.001
Level 2	0.96	0.188	1.45	<0.001
Level 1	1.06	0.095	1.93	<0.001
No qualifications	1.78	<0.001	3.72	<0.001
Other	0.96	0.267	1.80	<0.001
<i>Family characteristics</i>				
Not married or cohabiting	2.27	<0.001	1.13	<0.001
Child(ren) below 4 years	1.13	<0.001	4.08	<0.001
<i>Quarterly regional unemployment rate</i>	1.08	<0.001	1.03	<0.001
<i>Region</i>	0.98	<0.001	1.00	0.009
<i>Quarterly dummies</i>	1.00	0.663	1.00	0.232
Pseudo R2	.	0.2892	.	0.2025
Number of observations	.	302114	.	301140

Data source: LFS 2002-5 (pooled quarters).

3.2.5. Economic activity in households containing long-term sick working-age adults

Twenty seven percent of working-age Pakistani households are 'workless', i.e. without a single working-age adult in paid employment. However, to analyse the associations between household worklessness and the presence of long-term sick working-age members, I restricted the analysis to households containing more than one adult, since household worklessness would otherwise be conflated with individual worklessness and obviate the value of taking a household perspective. Twenty five percent of multiple-person working-age Pakistani households are workless. The prevalence of worklessness is even higher in households containing long-term sick adults. In multiple-member Pakistani households containing no adults reporting ill-health, the prevalence of worklessness is 18%, compared with 33% in households containing adult(s) reporting long-term ill-health and 38% in households containing adult(s) reporting activity limitations. In the general population these proportions are 10%, 18% and 23% respectively.

Table 3.10. shows the rates of worklessness in multiple-member households according to the health status of their adult members, for each of the major ethnic groups (p.77). Pakistani, Bangladeshi and Black African households stand out for having the highest levels of worklessness compared with other groups. By comparison, White British, Indian and Chinese households have the lowest rates of worklessness across health status. The same associations between household worklessness and the presence of long-term sick adults are therefore seen across ethnic groups, but the Pakistani and Bangladeshi households have the highest levels of worklessness irrespective of the health of their members.

Table 3.10: Percentages of workless households according to presences of members reporting long-term ill-health and activity limitations by ethnic group

	No working-age person reports ill-health		Households containing one or more persons reporting long-term ill-health		Households containing one or more persons reporting activity limitations	
	Percentage workless	Number of households	Percentage workless	Number of households	Percentage workless	Number of households
Pakistani	18%	924	33%	872	38%	706
Overall	10%	109,246	18%	78,285	23%	51,569
White British	9%	92,268	17%	68,205	22%	44,549
Indian	6%	1,849	17%	1,169	20%	886
Bangladeshi	23%	377	43%	313	49%	243
Black Caribbean	19%	1,138	25%	664	31%	424
Black African	29%	1,291	44%	445	47%	290
Chinese	20%	485	18%	137	23%	75
Mixed/Other	13%	10,914	25%	6,480	31%	4,396

Note: The sample of households was restricted to working-age multiple-member households. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person.
Data source: HLF5 2002-4.

The presence of long-term sick adults may impact on the chances of other household members being in paid employment, and therefore on the combined economic activity status of the household. Adult long-term ill-health seems to be particularly associated with the inactivity of other adult household members rather than their unemployment or a combination of the two. In households where there are no adults reporting long-term ill-health, 8% are entirely inactive, compared to 1% entirely unemployed and 1% a combination of unemployed and inactive. By contrast, in households where there is one or more adult reporting long-term ill-health, 15% are entirely inactive, 1% are entirely unemployed and 2% are a combination. In households where there is one or more adult reporting activity limitations, 26% are entirely inactive, 1% entirely unemployed and 4% a combination. The same patterns were seen across all of the ethnic groups (hence the results are not shown).

These household patterns are affected by multiple points of contrast between the ethnic groups in their socio-economic characteristics and composition (see Appendix 3 for descriptive statistics on the households by ethnic group). I used multivariate logistic regression to explore the relative contribution of long-term ill-health, ethnic group and other relevant factors to these patterns of household worklessness. The results are presented in Table 3.11. (p.80). In Model 1, the probability of household worklessness is modelled controlling for the health of adult household members and ethnic group. This model indicates whether there are significant ethnic differences in the prevalence of household worklessness after controlling for the health of the adult members. The results show that the Pakistani households still have higher chances of household worklessness compared with other ethnic groups, after controlling for the health of the adult members. Apart from the Indian households, the ethnic minority households are much more likely to be workless than the White British households, particularly the Bangladeshi and Black African households.

In Model 2, additional controls for household composition are included (the total number of household members, type of household, the presence of elderly people and the presence of children under 15 years), which have all been demonstrated to be relevant to combined household economic activity status in the literature (see Walling 2004). An important omission from the model is the sex of the person(s) reporting long-term ill-health. It was beyond the scope of the quantitative analysis to analyse whether the associations with household worklessness were differentiated by the sex of the person(s) reporting long-term ill-health, since roughly a tenth of the households contained multiple adults reporting long-term ill-health. It was therefore not

possible to determine whether household worklessness was more strongly associated with long-term ill-health in men or women. However, such processes emerged to be crucial in the qualitative component of the study, and Chapter 7 explores the gendered impact of long-term ill-health for the combined economic activity of the household in detail.

The inclusion of household characteristics increases the size of the odds ratios for the health status factors and for the ethnic minority groups, suggesting that the influence of these factors over household worklessness had been underestimated as a result of differences in household composition that cut across ethnic groups. This was particularly the case for the Black Caribbean households, in which the higher levels of worklessness could be attributed overwhelmingly to the higher rates of lone parenthood, and health status was a relatively less important factor. A similar, but less stark effect can also be seen in the Black African households.

In Model 3, additional socio-economic factors are included (the education of the household reference person, housing tenure, regional unemployment rate and geographic region). As noted in the previous section, an important omission is occupational class, which I was not able to include due to the endogeneity of the category of never worked or long-term unemployed with the outcome variable. The inclusion of the socio-economic factors reduces the size of the odds ratios for the health status variables, suggesting that some of the observed association between adult ill-health and household worklessness can be attributed to the poorer education, housing tenure and regional unemployment characteristics reported by the households containing long-term sick members. The inclusion of the socio-economic factors also reduces the odds ratios for the Bangladeshi and Black African groups, suggesting that their higher rates of household worklessness can be partly attributed to their generally poorer socio-economic status. However, as we also saw in the individual-level analysis of economic activity, the chances of worklessness in Pakistani households remained high and did not reduce after taking account of the socio-economic differentiation between the groups. As I noted before, re-running the regression analyses separately for the ethnic groups suggested that this may be because Pakistani employment is less related to education and housing than for other groups like the Bangladeshis.

Table 3.11: Estimates from logistic regression indicating the effects of relevant factors on household worklessness

	Model 1		Model 2		Model 3	
	OR	P-value	OR	P-value	OR	P-value
Health of adults in household						
One or more person(s) with long-term ill-health	1.11	<0.001	1.43	<0.001	1.36	<0.001
One or more person(s) with activity limitations	2.74	<0.001	3.39	<0.001	2.92	<0.001
Ethnicity						
White British	1		1		1	
Indian	0.8	<0.001	0.88	0.197	1.08	0.435
Pakistani	2.25	<0.001	2.86	<0.001	2.94	<0.001
Bangladeshi	3.33	<0.001	4.56	<0.001	1.78	<0.001
Black Caribbean	2.07	<0.001	0.96	0.639	0.71	<0.001
Black African	4.36	<0.001	3.06	<0.001	1.86	<0.001
Chinese	2.23	<0.001	3.63	<0.001	3.5	<0.001
Mixed/Other	1.64	<0.001	1.79	<0.001	1.61	<0.001
Household characteristics						
Number of people in household			0.99	0.89	0.96	0.004
Household type						
Couple with dependent children			1		1	
Couple without children			3.34	<0.001	3.14	<0.001
Couple with non-dependent children			0.64	<0.001	0.53	<0.001
Lone parent with dependent children			19.2	<0.001	9.31	<0.001
Lone parent with non-dependent children			3.29	<0.001	1.7	<0.001
Complex (multiple family) household			2.52	<0.001	1.77	<0.001
Household containing elderly person(s)			4.9	<0.001	7.02	<0.001
Household containing child(ren) under 15			1.84	<0.001	1.53	<0.001
Socio-economic factors						
Education						
Degree + higher level diplomas					1	
Level 3 + apprenticeships					1.38	<0.001
Level 2					1.3	<0.001
Level 1 [equivalent to GCSE]					1.71	<0.001
Other					1.39	<0.001
No qualifications					2.85	<0.001
Housing						
Owner occupied					1	
Rented privately					4.32	<0.001
Social housing					6.23	<0.001
Regional unemployment rate					1.06	<0.001
Region					0.98	<0.001
Quarterly dummies					0.98	0.039
Pseudo R2		0.05		0.23		0.33
Number of observations		187531		187531		186843

Note: Households were restricted to working-age multiple-member households. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person. Education was assigned to the household on the basis of the qualifications of the household reference person. The standard errors were adjusted to allow for repeat observations on single households.

Data source: HLFS 2002-4.

3.2.5.1. Differential associations between the health of household members and household combined economic activity

To explore whether there might be differentials in the association between the health of household members and household worklessness according to social factors such as ethnic group, education and housing tenure, I tested for interaction effects in the multivariate regression models. As in the individual-level analysis, the investigations around interactions produced no evidence for differentials in the associations between the health of adult household members and household worklessness by ethnic group. The likelihood ratio tests carried out on the un-clustered data indicated that the inclusion of interactions between ethnic group and the health of household members improved the models with a probability of less than $p < 0.01$. However, as in the individual-level analysis, the odds ratios for the individual interaction terms were little different from one and the Wald statistics were insignificant and inconsistent. There is therefore no clear evidence that the association between the health of household members and household worklessness is any different for a Pakistani household than for a White British household after accounting for the ethnic differences in household composition and socio-economic factors. The investigations also produced no clear evidence for differentials in the associations between the health of household members and household worklessness across housing tenure.

As we found previously, however, the investigations around education were suggestive of interaction effects. The likelihood ratio tests on the un-clustered data showed that the interaction terms between education and the health status of adult household members improved the likelihood of the models with a statistical significance below $p < 0.01$. The interaction terms serve to increase the association between long-term ill-health and worklessness quite specifically for households in which the household reference person has no qualifications, although there was also an increased association for level 3 qualifications. There was a less consistent step-by-step increase in the interactions with education than in the individual-level analysis, as the interaction terms for level 2 and level 1 qualifications were not significantly raised above the degree-qualified group. These patterns are illustrated in Table 3.12 (p.82).

Table 3.12: Estimates from multinomial logistic regression indicating interaction effects between activity limitations and education in modelling household worklessness

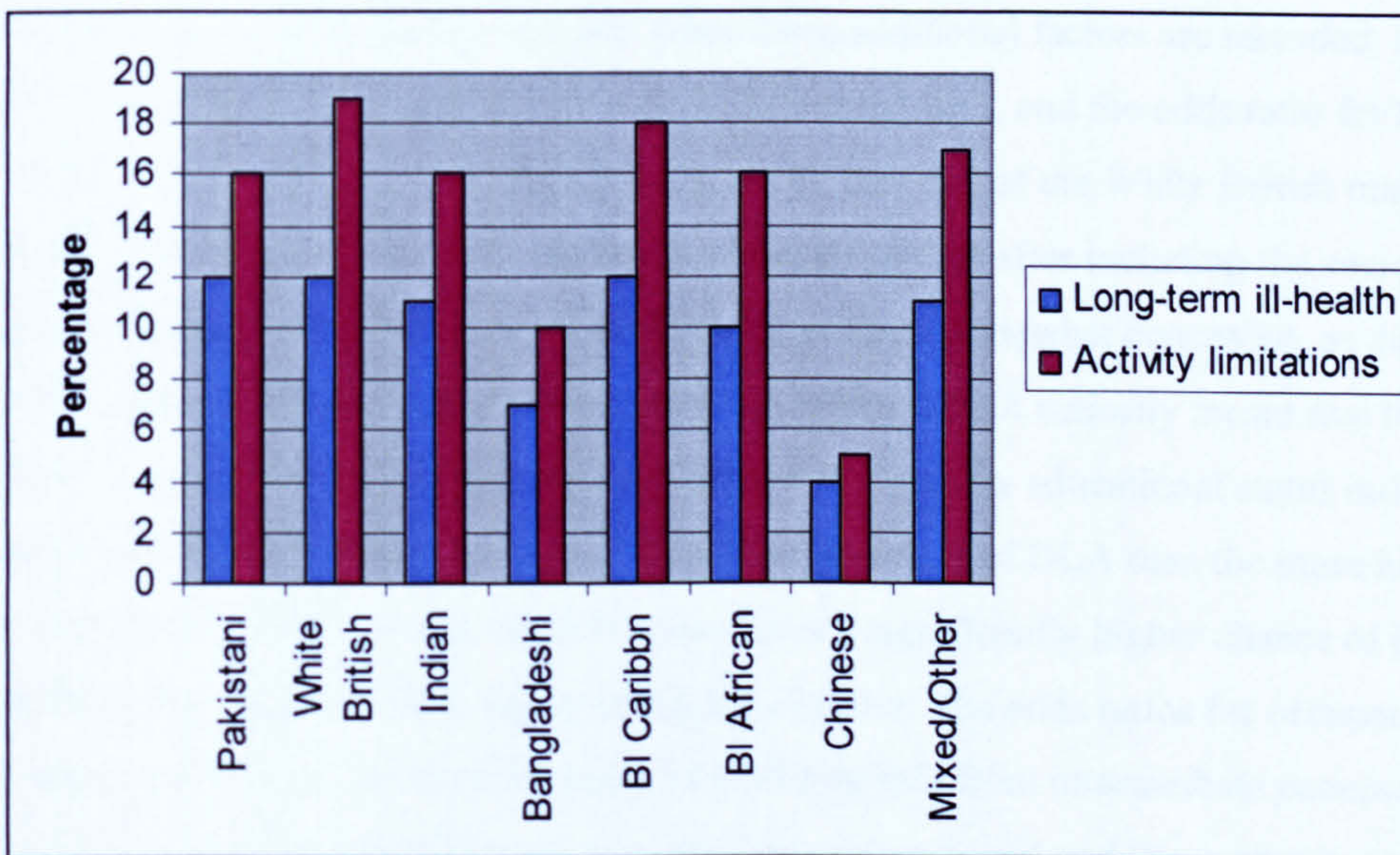
	OR	P-value
Health of adults in the household		
One or more person(s) with long-term ill-health	1.36	<0.001
Interactions between activity limitations and education		
No adult(s) with activity limitations X Degree + higher level diplomas	1	
No adult(s) with activity limitations X Level 3 + apprenticeships	1.23	<0.001
No adult(s) with activity limitations X Level 2	1.26	<0.001
No adult(s) with activity limitations X Level 1	1.65	<0.001
No adult(s) with activity limitations X Other qualifications	1.23	<0.001
No adult(s) with activity limitations X No qualifications	2.26	<0.001
Adult(s) with activity limitations X Degree + higher level diplomas	2.23	<0.001
Adult(s) with activity limitations X Level 3 + apprenticeships	3.74	<0.001
Adult(s) with activity limitations X Level 2	3.06	<0.001
Adult(s) with activity limitations X Level 1	4.09	<0.001
Adult(s) with activity limitations X Other qualifications	3.85	<0.001
Adult(s) with activity limitations X No qualifications	8.66	<0.001
Ethnicity		
White British	1	
Indian	1.07	0.473
Pakistani	2.89	<0.001
Bangladeshi	1.81	<0.001
Black Caribbean	0.72	0.001
Black African	1.88	<0.001
Chinese	3.51	<0.001
Mixed/Other	1.59	<0.001
Household characteristics		
Household composition		
Couple with dependent children	1	
Couple without children	3.14	<0.001
Couple with non-dependent children	0.51	<0.001
Lone parent with dependent children	9.40	<0.001
Lone parent with non-dependent children	1.69	<0.001
Complex (multiple family) household	1.76	<0.001
Number of people in household	0.96	0.008
Household containing elderly persons	7.09	<0.001
Household containing child(ren) under 15	1.53	<0.001
Socio-economic factors		
Housing		
Owner occupied	1	
Rented privately	4.33	<0.001
Social housing	6.23	<0.001
Regional unemployment rate	1.08	<0.001
Region	0.99	<0.001
Quarterly dummies	0.99	0.066
Pseudo R2		0.32
Number of observations		186843

Data source: HLFS 2002-4.

3.2.6. Levels of receipt of DLA among long-term sick working-age adults

Although we cannot directly model a person's eligibility for DLA using the LFS, those eligible should at least acknowledge having long-term ill-health. The analysis is therefore restricted to the individuals who reported long-term ill-health. Figure 3.5. illustrates the rates of DLA receipt among the respondents reporting long-term ill-health and activity limitations. Overall, 12% of long-term sick Pakistanis and 16% of those with activity limitations report receiving DLA. This was somewhat less than the respective 13% and 19% in the general population. Levels of DLA receipt were highest in the White British group and lowest among the Bangladeshis and Chinese.

Figure 3.5: Percentages of working-age adults with long-term ill-health and activity limitations by ethnic group receiving DLA



Data source: LFS 2002-05 (pooled quarters).

I carried out multivariate logistic regression in the subpopulation reporting long-term ill-health to identify the extent to which these ethnic differences in DLA receipt might be attributed to cross-cutting differences in age, the severity of the health conditions, and the socio-economic status of the respondents. Table 3.13. shows two models of the receipt of DLA (p.85). In Model 1, the probability of the respondent being in receipt of DLA is modelled controlling for the effects of age, health status and ethnic group. This model indicates whether there are significant ethnic differences in the use of DLA after controlling for group differences in health status. The results show that age generally increases the chance of being in receipt of DLA, as does having activity limitations and an increasing number of health conditions. The differences between men and

women are neither appreciable nor statistically significant. The odds ratios for the ethnic minority groups are generally below 1, indicating that the ethnic minority groups are less likely to be in receipt of DLA than their White British counterparts after the other relevant characteristics have been held constant. However, only for Pakistanis and Bangladeshis is the decreased chance of DLA receipt significantly lower from in the ethnic majority.

In Model 2, the probability of the respondent being on DLA is modelled taking account of socio-economic factors in addition to age, health and ethnic group. Education, occupational class, and the use of other benefits may affect a person's willingness to use benefits, knowledge about and familiarity with the benefits system, and their perception of needing the benefit. Unlike previously, I was able to include occupational class in the analysis of DLA because it was not endogenous to the outcome variable. After these additional factors are included, the odds ratios for the ethnic minority groups move even further below 1, and the odds ratio for the Black African group also becomes significantly lower than that of the White British majority. The decrease in the odds ratios for the ethnic minority groups after including the socio-economic factors suggests that their lower use of DLA had been somewhat concealed, as their generally lower socio-economic status compared to the White British majority meant that they were more likely to be in receipt of DLA anyway. The odds ratios for educational status indicate that those with lower qualifications are more likely to be in receipt of DLA than the more highly educated. In particular, people with no qualifications have a significantly higher chance of being in receipt of DLA than people with a degree or higher diploma. The odds ratios for occupational class indicate quite a consistent relationship in which people from intermediate occupations, semi-routine or routine manual classes, the long-term unemployed and those who have never worked are steadily more likely to be in receipt of DLA than those in managerial or professional occupations. Finally, DLA receipt is much more likely among those who are also in receipt of IS, an indicator of financial poverty, whereas it is less likely among those in receipt of unemployment benefits or NI credits. This intriguing finding implies that DLA receipt is more significantly associated with financial poverty than with familiarity with the benefits system per se. The results therefore support the hypothesis that receipt of DLA increases in relation to the need for the benefit, consistent with work indicating that the receipt of DLA is concentrated in low-income households in which there is more pressure to take up the benefit (Noble, Platt et al. 1997).

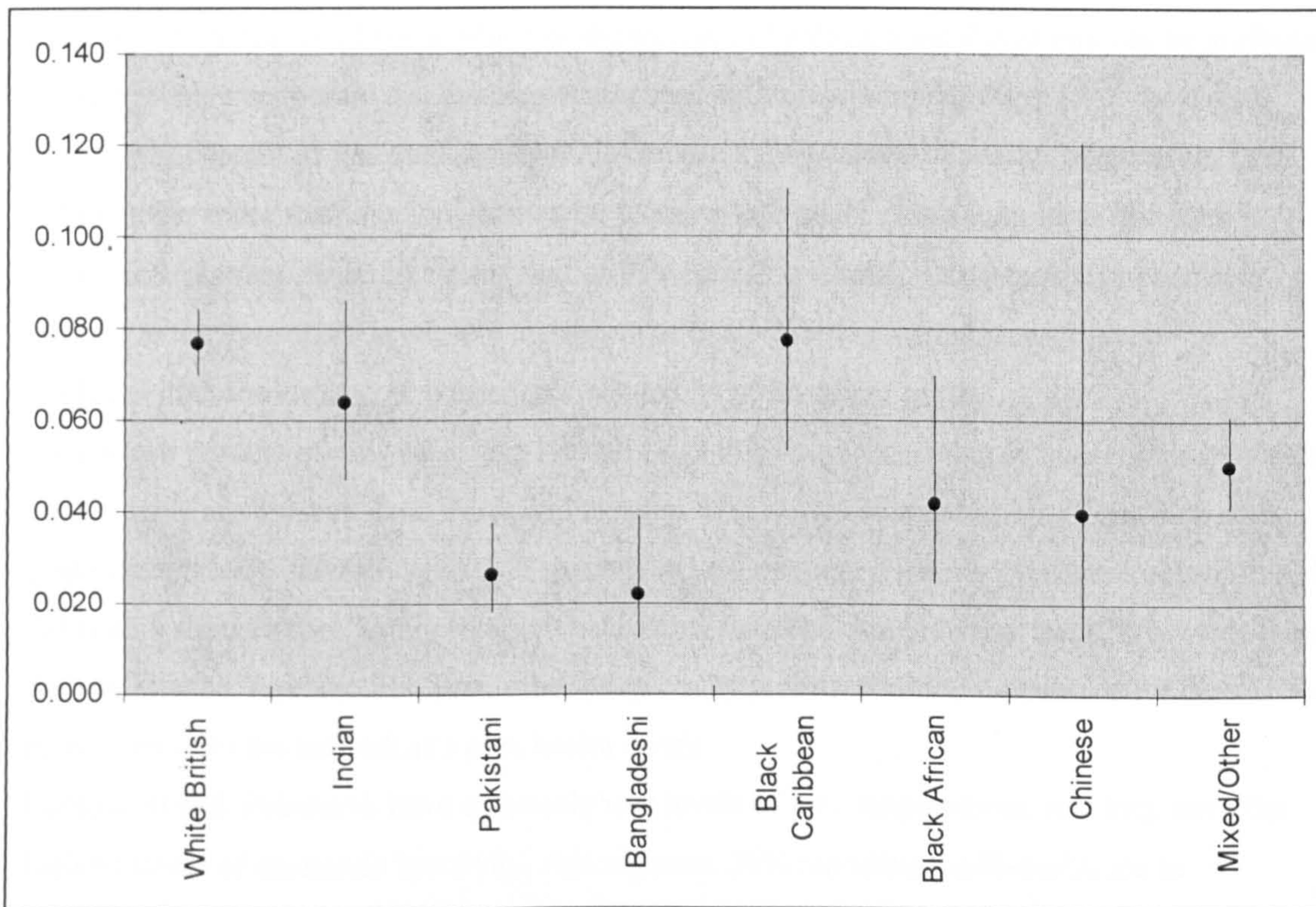
Table 3.13: Estimates from multivariate logistic regression indicating the effects of various characteristics on the receipt of DLA among respondents with long-term ill-health

	Model 1		Model 2	
	OR	P-value	OR	P-value
<i>Age</i>	0.98	0.008	0.99	0.262
<i>Age squared</i>	1.01	0.169	1	0.771
<i>Sex</i>	0.96	0.156	0.95	0.024
<i>Health factors</i>				
Activity limitations	8.91	<0.001	6.36	<0.001
Number of health conditions	1.45	<0.001	1.41	<0.001
<i>Ethnicity</i>				
White British	1		1	
Indian	0.86	0.207	0.82	0.213
Pakistani	0.65	0.002	0.32	<0.001
Bangladeshi	0.52	0.015	0.26	<0.001
Black Caribbean	1.1	0.515	0.99	0.992
Black African	1	0.997	0.54	0.027
Chinese	0.5	0.171	0.51	0.51
Mixed/Other	1.16	0.01	0.94	<0.001
<i>Socio-economic factors</i>				
<i>Education</i>				
Degree + higher level diplomas			1	
Level 3 + apprenticeships			0.89	0.103
Level 2			1.06	0.429
Level 1			1.14	0.069
Other			0.91	0.233
None			1.37	<0.001
<i>NSSEC</i>				
Managerial & professional			1	<0.001
Intermediate			1.2	0.005
Routine & manual			1.43	<0.001
Never worked or long-term unemployed			4.03	<0.001
Full-time student			2.48	<0.001
<i>Other benefits</i>				
Income Support			2.63	<0.001
Unemployment benefits & NI credits			0.47	<0.001
<i>Region</i>				
Quarterly dummies			1.01	0.07
Pseudo R2		0.184		0.224
Number of observations		151873		127935

Data source: LFS 2002-5 (pooled quarters).

Finally, I calculated the predicted probabilities of being in receipt of DLA, which estimate the marginal impact of ethnicity on the use of DLA after matching for the other factors included in the regressions. Figure 3.6. illustrates that after controlling as much as possible for the need for the benefit, Pakistanis and Bangladeshis have substantially lower probabilities of using DLA compared with their matched White British counterparts. The Black Africans and Chinese respondents also have lower chances of using DLA. The Black Caribbeans stand out as the only ethnic minority group whose use of DLA is comparable with that of the White British majority.

Figure 3.6: Predicted probabilities for the receipt of DLA among those reporting long-term ill-health by ethnic group



Notes: Probabilities are predicted from comparisons between ethnic groups assuming the baseline of a person with mean age and age squared; activity limitations; mean number of specific health conditions; level 3 qualifications or apprenticeships; routine and manual occupational class; and not on Income Support, unemployment benefits or NI credits. The error bars show the 95% confidence intervals. Data source: LFS 2002-05 (pooled quarters).

3.3. Conclusions and implications

The quantitative findings concerning the levels and differentials in long-term ill-health and livelihood outcomes among Pakistanis are diverse. Here, I draw out the most meaningful findings and their implications for the following ethnographic chapters of the thesis:

- I. A quarter of working-age Pakistanis reported long-term ill-health and 19% reported activity limitations. Ill-health among Pakistanis arises at an earlier age than in the general population, and it appears to be more severe, as indicated by the higher prevalence of activity limitations and multiple health conditions. Much of the excess ill-health among Pakistanis can be attributed to their relative economic disadvantage compared with other ethnic groups.
- II. Forty eight percent of Pakistani households contain a long-term sick working-age adult, and 15% contain more than one long-term sick working-age adult. Adult long-term ill-health is therefore a problem faced by nearly half of Pakistani households. Long-term ill-health also clusters at the household level, and the extent of this clustering is statistically greater in Pakistani households than in households headed by other ethnic groups.
- III. Ninety two percent of long-term sick working-age Pakistanis are living in households in which other people are present. Two thirds of Pakistani households containing long-term sick adults contain dependent children aged 0-15 years and 12% contained elderly persons. Long-term sick Pakistanis are therefore highly likely to have other household members at hand to provide them with assistance. Equally, however, other people may present additional demands for care to be reconciled with the individual's own health needs.
- IV. Long-term sick Pakistanis have extremely low levels of paid employment, and they have the highest levels of economic inactivity. Among men, 76% reporting no ill-health are in employment compared with 42% of long-term sick men and just 33% of with activity limitations. Among the men who are out of employment, long-term sick Pakistanis are particularly likely to be inactive rather than unemployed, suggesting that most of them are not actively looking for work. Among long-term sick Pakistani women, levels of employment are even lower. Just 31% of women reporting no ill-health were in employment, going down to 15% for those with long-term ill-health and 10% for those with activity limitations. However, despite differences in absolute levels, the relative impact of long-term ill-health on economic activity appears to be similar across the ethnic groups. The social factors corresponding to a greater relative effect of long-term ill-health on employment are higher age; male sex; low

levels of qualifications, especially for people with level 1 qualifications (equivalent to GCSE) or no qualifications at all; and living social housing compared to owner-occupied or privately rented properties. Pakistanis will be disproportionately affected by the interaction effects with low or no qualifications due to their relatively poor educational status compared with other groups.

- V. Levels of worklessness at the household level are also associated with long-term ill-health. A third of Pakistani households containing adult(s) with long-term ill-health are completely workless, and so are 38% of households containing adult(s) with activity limitations, compared with 18% of Pakistani households with no adults reporting ill-health. Adult ill-health is therefore associated with economic inactivity among other adult household members, and contributes to a polarisation between workless households and households containing multiple-earners. The relative impact of ill-health on household worklessness was again found to be differentiated not by ethnic group, but by education. However, the interactions with education will disproportionately affect Pakistani households. The higher levels of ill-health in Pakistani households also mean that this process will affect Pakistanis more than other ethnic groups.
- VI. Twelve percent of Pakistanis with long-term ill-health and 16% with activity limitations were in receipt of DLA. However, after adjusting for the generally lower socio-economic status of Pakistanis compared with their counterparts in other ethnic groups, the chances of DLA receipt among Pakistanis were found to be strikingly lower than in the other ethnic groups.

The findings imply that long-term ill-health is an important factor contributing to economic polarisation between individuals and households. People who are poorly qualified or living in rented housing, particularly social housing, are more likely to experience long-term ill-health. They are also more likely to experience unemployment or inactivity pending on ill-health. Furthermore, long-term ill-health contributes to a 'clustering' of worklessness within households – particularly inactivity rather than unemployment. Households containing long-term sick adults are less likely to benefit from the employment of other household members, as the employment of others is hindered by their involvement in the provision of assistance and care. The chances of household worklessness pending on ill-health are also differentiated by social factors. The impact of long-term ill-health is therefore differentiated, and its effects are differentiating in turn.

The consequences of ill-health are exacerbated among Pakistanis, but through complex routes and counterintuitive processes. Although they are better placed to access assistance and care from other households than, for example, the White British, Pakistanis are affected by higher levels of

ill-health, disproportionately high levels of unemployment and inactivity, and appear not to access health-related benefits as highly as people from other ethnic groups. Somewhat surprisingly, the impact of ill-health on economic activity seems to be no more or no less for Pakistanis than in other ethnic groups after taking account of the cross-cutting of socio-economic and familial differences between the groups. The important factors differentiating the impact of ill-health cut across ethnic groups: age, sex, education and housing tenure. However, the interactions with poor education will affect Pakistanis more than other ethnic groups.

The findings imply that a substantial part of how Pakistani ethnicity influences the experience of long-term ill-health is attributable to structural and material factors. However, it is important not to overstate the conclusions here: the analyses cannot identify precisely how much of the observed ethnic differences can be attributed to broader socio-economic inequalities. Kaufman and Nazroo have pointed out the logical inconsistencies in attempting to quantitatively apportion ethnic variation between socio-economic factors and 'pure' ethnic effects or penalties. The attempt to 'control away' ethnicity through other factors is misleading, often suggesting a spurious effect of ethnicity due to residual confounding from other, poorly specified and proxied intermediates (Kaufman, Cooper et al. 1997; Kaufman and Cooper 2001; Nazroo 2003). Furthermore, as I argued in Chapter 1, this logic desocialises and dehistoricises the processes by which material factors come to differentially affect certain ethnic groups, and elides questions about how socio-economic status is produced and reproduced in different ethnic groups.

This chapter shows that the associations between long-term ill-health and livelihoods are differentiated by age, sex, educational status, and housing tenure. It highlights the importance of taking a household-level analysis and examining the links between individual and household processes in the consequences of long-term ill-health. To develop these findings, the ethnographic chapters of the thesis take forward the analysis of variation in the economic impact of long-term ill-health, focussing particularly on gender, generation and material context.

Chapter 4. Qualitative methods

4.1. Introduction

The relationships between long-term ill-health and livelihoods are too complex to disentangle using only survey data. The qualitative component of the study permits a more multi-layered and contextualised understanding of the social process of becoming long-term sick; an understanding of the multi-dimensional, dynamic and intangible qualities of livelihoods; and the relational and variable influence of class distinctions, gender and being Pakistani, as well as the emergent meanings created through these categories in everyday life. With its interpretive approach, the qualitative study allows me to challenge the interpretation of the quantitative data, and potentially uproots the assumptions framing the analyses. It gives an understanding of process, life experience, social variation and complexity, adding rich detail and meaning to bare bones of the quantitative analysis – what Geertz calls ‘thick description’ (Geertz 1975). However, the qualitative component aims to avoid the uncritical interpretivism that is common in medical sociology and medical anthropology. Silverman, for example, finds fault with the excessive emphasis on “how people ‘see things’ and ignor[ing] the importance of how people ‘do things’” (Silverman 1998) (p.105). The Comaroffs, similarly, suggest that ethnography should traffic in “analytical constructions rather than unverifiable subjectivities” (Comaroff and Comaroff 1992) (p.12). My approach therefore draws from the principles of ‘critical ethnography’. This requires capturing behaviour in its ‘natural’ context as well as more introspective meanings and understandings, and explicitly analysing the testimony of the informants in relation to the broader local, historical and structural context (Wainwright 1997).

4.2. Study setting

The qualitative data were mostly collected from Newham, an East London borough located socially and geographically between the inner-city estates of Tower Hamlets and the leafy commuter suburbs of Essex (see Figure 4.1.) (p.91). Newham is a predominantly working-class locality and has very high rates of unemployment and economic inactivity as a consequence of deindustrialization and the slow expansion of the service sector. It is the eleventh most deprived local authority in England and Wales and the fourth most deprived in London (London Borough of Newham 2006). However, the economic recessions and booms of the 1980s and 1990s have created polarisation in Newham as elsewhere, creating an increasing population of white collar

professionals and owner occupiers alongside marginalisation among people with poor qualifications, ex-industrial workers and ethnic minority groups (Rix 1997).

Figure 4.1: The borough of Newham within London



Newham has the largest proportion of non-White population of any local authority in the country: more than 60% of its population is from a non-White ethnic group. In 2001 Newham was home to 19,000 ethnic Pakistanis, or 9% of the borough (London Borough of Newham 2006).

Newham was created in 1985 through a boundary rearrangement, incorporating the old royal boroughs of West Ham and East Ham. This part of East London was the industrial heartland of the South-East, attracting migrant workers from Ireland, Germany, Italy, Poland, Russia and Lithuania from the 19th century, followed by later flows of Jews originating from Germany and Eastern Europe, South Asian *lascars* (sailors and ship-hands) and demobbed Commonwealth troops from the Caribbean and Africa. By the 1930s, the Black community in Canning Town was the largest in the London (Eastside Community Heritage n.d.; Widdowson and Block n.d.). The larger waves of labour migration in the post-war era, flows of family reunification and more recent large-scale migration of students, asylum seekers and refugees have built upon this existing social geography of migration and settlement (London Borough of Newham 2002).

Plate 1: Birthplace of immigrants according to the 1901 census. The first South Asian immigrants in East London were sailors and ship-hands (*lascars*) who jumped ship to try their fortunes in London.

Country of birth of foreigners and naturalised British subjects enumerated in the City of London and each metropolitan borough and in 14 extra-London urban districts—(continued).

City, metropolitan borough, or urban district.	Europe.															America.		Born abroad (country not stated or at sea.)	Number.	Percentage to total population (male or female).	Percentage to total foreigners, etc. (male or female in the Administrative County.)	Naturalised British subjects (included in col. 21).			
	Austria.	Hungary.	Belgium.	Denmark, Norway and Sweden.	France.	Germany.	Holland.	Italy.	Portugal and Spain.	Russia (including Russia).	Russian Poland (not included in previous col.).	Serbia, Roumania, Bulgaria, Montenegro and Greece.	Switzerland.	Turkey (including Asiatic Turkey).	Asia.	Africa.	United States.						Other countries.		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	
<i>Extra-London urban districts.</i>																									
Arton .. M.	15	—	3	15	45	140	18	26	7	13	4	—	6	29	5	12	—	16	—	—	—	—	—	—	33
Arton .. F.	9	—	9	17	70	89	8	17	10	3	—	—	—	30	3	3	—	18	—	—	—	—	—	—	17
Croydon (C.B.) .. M.	27	2	21	21	121	217	15	69	10	31	—	—	—	45	5	11	—	18	—	—	—	—	—	—	162
Croydon (C.B.) .. F.	6	1	20	18	86	147	11	27	6	23	—	—	—	34	3	11	—	36	—	—	—	—	—	—	102
Ealing (M.B.) .. M.	5	2	1	15	52	83	8	12	7	18	—	—	—	26	3	9	—	35	—	—	—	—	—	—	39
Ealing (M.B.) .. F.	10	—	—	22	70	83	8	12	4	15	—	—	—	37	1	8	—	25	—	—	—	—	—	—	26
East Ham (M.B.) .. M.	31	3	15	73	20	213	52	29	4	80	—	—	—	4	—	—	—	143	—	—	—	—	—	—	11
East Ham (M.B.) .. F.	19	2	2	26	25	126	46	13	2	77	—	—	—	7	—	—	—	23	—	—	—	—	—	—	66
Edmonton .. M.	7	4	1	18	13	63	14	8	4	4	—	—	—	1	—	—	—	12	—	—	—	—	—	—	34
Edmonton .. F.	1	—	—	6	12	36	2	1	—	6	—	—	—	—	—	—	—	12	—	—	—	—	—	—	8
Enfield .. M.	4	—	3	53	14	43	2	4	3	4	—	—	—	1	—	—	—	6	—	—	—	—	—	—	3
Enfield .. F.	4	—	1	20	14	34	1	—	2	4	—	—	—	13	—	—	—	2	—	—	—	—	—	—	17
Hornsey (M.B.) .. M.	41	7	16	41	73	476	41	28	16	42	13	—	—	123	8	—	—	34	—	—	—	—	—	—	122
Hornsey (M.B.) .. F.	14	5	13	44	81	236	40	7	5	24	8	—	—	32	—	—	—	30	—	—	—	—	—	—	54
Hornsey (M.B.) .. F.	10	2	2	23	19	132	25	12	4	22	5	—	—	18	—	—	—	40	—	—	—	—	—	—	34
Ilford .. M.	10	—	6	17	16	78	18	4	3	14	6	—	—	11	—	—	—	10	—	—	—	—	—	—	22
Ilford .. F.	26	3	8	21	21	240	18	11	8	26	15	—	—	30	—	—	—	4	—	—	—	—	—	—	54
Leyton .. M.	6	—	1	7	20	117	12	11	2	17	—	—	—	5	—	—	—	13	—	—	—	—	—	—	20
Leyton .. F.	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Tottenham .. M.	42	4	10	25	38	361	34	43	11	146	117	—	—	25	—	—	—	51	—	—	—	—	—	—	62
Tottenham .. F.	23	1	7	10	64	163	25	24	8	150	78	—	—	17	—	—	—	24	—	—	—	—	—	—	32
Walthamstow .. M.	20	2	14	21	41	209	20	30	6	34	10	—	—	18	—	—	—	16	—	—	—	—	—	—	45
Walthamstow .. F.	24	1	4	7	34	184	11	18	1	18	7	—	—	8	—	—	—	7	—	—	—	—	—	—	18
West Ham (C.B.) .. M.	80	7	34	140	52	628	49	117	10	124	150	21	—	15	—	—	—	41	—	—	—	—	—	—	131
West Ham (C.B.) .. F.	27	—	18	27	35	337	25	37	8	94	108	10	—	6	—	—	—	10	—	—	—	—	—	—	67
Willesden .. M.	63	34	26	55	103	533	54	80	7	119	63	22	—	57	—	—	—	36	—	—	—	—	—	—	214
Willesden .. F.	36	5	29	32	146	374	46	38	6	70	38	13	—	26	—	—	—	31	—	—	—	—	—	—	108
Wimbledon (M.B.) .. M.	9	5	11	17	46	163	16	15	15	5	—	—	—	18	—	—	—	14	—	—	—	—	—	—	37
Wimbledon (M.B.) .. F.	4	1	13	31	63	96	24	11	11	3	—	—	—	6	—	—	—	21	—	—	—	—	—	—	15

III. GENERAL STATISTICS.

Source: 'People who moved to Newham' resource book, local studies department, Stratford library.

Plate 2: A group at the Coloured Men's Institute in Canning Town, 1927. Unemployment in the 1920s was high and immigrants were blamed. Kamal Chunchie, a Methodist pastor from Sri Lanka, opened the Coloured Men's Institute to create a space where Black people could escape from White hostility.



Source: London Borough of Newham (2002), p.17.

Plate 3: Canning Town synagogue, Barking Road, up for sale in 1983, built in 1923. Jews from Germany and Eastern Europe were among the first migrants to settle in the East End in the late 19th century.



Source: 'People who moved to Newham' resource book, local studies department, Stratford library.

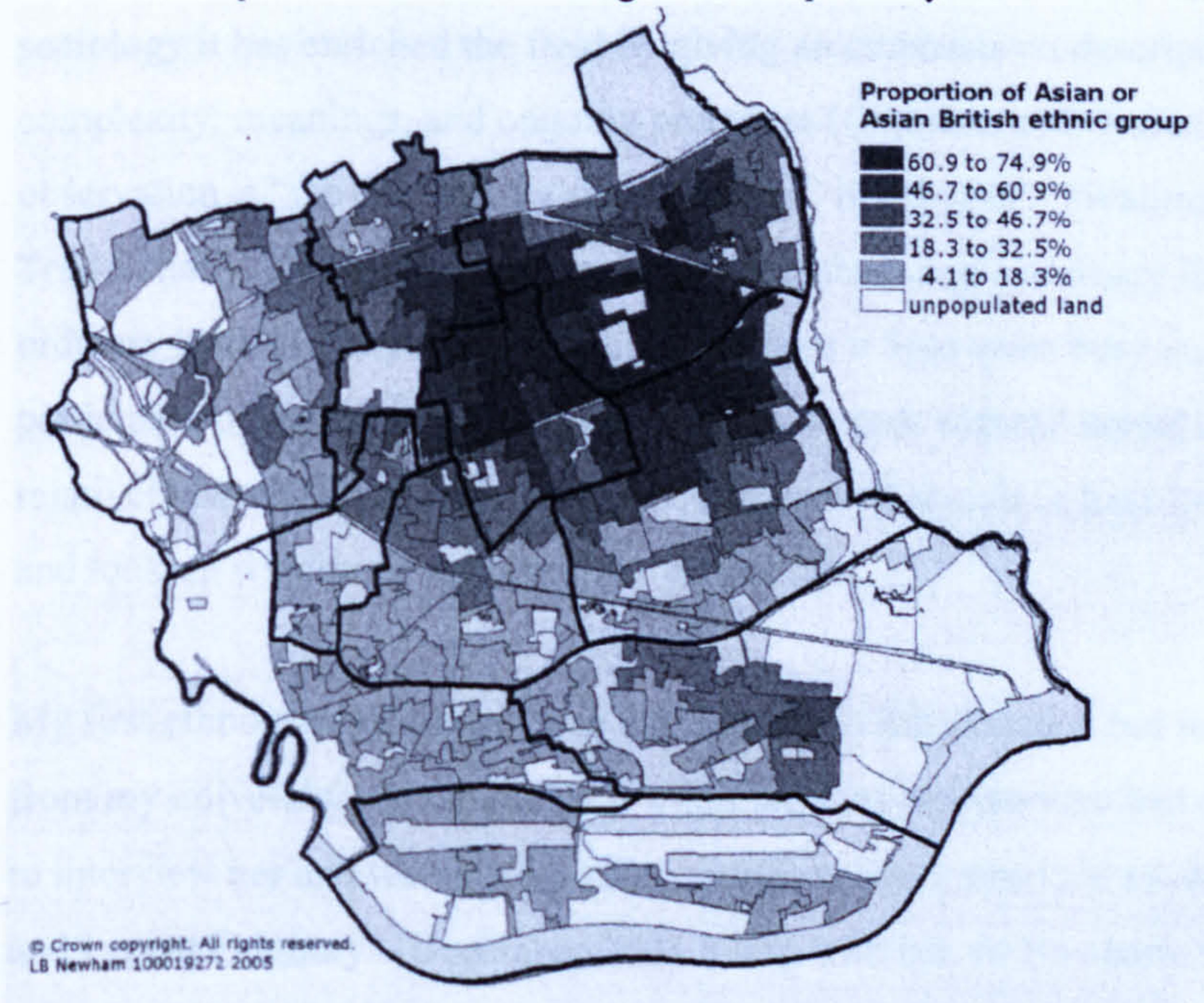
Plate 4: Canning Town mosque, Barking Road, 2007. The upward mobility of the Jewish population in East London permitted them to move to North London. Many of their synagogues were bought up by South Asians and converted into mosques.



Source: author's own.

The earliest flows of labour migration from Pakistan to East London originated from Mirpur district in Azad Kashmir, and were subsequently linked to migration flows from the neighbouring districts of Jhelum, Rawalpindi and Gujrat in the north of Punjab. Lesser numbers of migrants also drew to East London from districts in the central Punjab, such as Faisalabad, Sargodha and Multan, as well as from Pakistan's major urban centres: Lahore and Sialkot, Karachi and Peshawar. Most of the early Pakistani labour migrants found work in small-scale factories and workshops run by Jewish or Asian patrons in Aldgate and Whitechapel before discovering more favourable terms of employment in the large factories surrounding the docks. A significant stream of Pakistanis migrated to East London after having first settled in the North of England (West Yorkshire, Lancashire) or the West Midlands, where they worked for a number of years in textile mills and foundries before being made redundant or simply moving on. Pakistani workers sustained the moribund industries of East London at a time when they would otherwise have been economically unviable, allowing workshops and factories to remain profitable through low pay and poor health and safety conditions. With the dismantling of industry in the 1980s thousands of Pakistanis were made redundant, prompting long-term unemployment, whilst others shifted to self-employment and the rental property market (K. Harriss 2006; Ahmad 2008a).

Plate 5: Residential clustering of Asian or Asian British population in Newham, 2006. The North-East of the borough suffered less bombing than West Ham and the docklands during the second world war, and contains little post-war council housing and more privately rented and owner-occupied properties.



Source: London Borough of Newham (2006), p.27.

The Pakistanis in Newham are still overwhelmingly working-class, and relatively badly off compared to their neighbours from other ethnic groups (Platt 2003a). Levels of owner-occupation are high (London Borough of Newham 2006), although this results partly from the history of racial discrimination in the rental housing market as well as in the council. In 1975 Councillor Bill Watts openly admitted that East Ham council had deliberately changed its housing policies to avoid housing Asian families, requiring claimants to have been resident in the borough for a year before being eligible for council housing: “the recent influx of Asians would have meant that in five years time we would have done nothing but give homes to Asians” (Newham Monitoring Project 1991) (p.5). As expected, the prevalence of long-term ill-health among Pakistanis is higher than in the general population in the borough (Pevalin 2003).

4.3. Data sources and data collection methods

The multiple data sources and data collection methods used in the qualitative component of the study are represented graphically in Figure 4.2. (p.98).

4.3.1. Participant-observation

Charmaz and Olsen observe that where participant-observation has been used in medical sociology it has enriched the field by giving an emphasis on descriptive detail, context, social complexity, meanings, and ongoing processes (Charmaz and Olesen 1997). Participant-observation is “the deceptively simple task of ‘hanging in’” (Wallman 1984) (p.42).

Traditionally, it involves year-round isolation from one’s ordinary life and immersion in the ordinary lives of others. In East London people’s lives were busy and compartmentalised, and participant-observation was bitty at best; I accessed ‘natural’ social life sporadically and in relatively restricted settings. However, I immersed myself in East London as much as possible, and took up whichever opportunities presented.

My first ethnographic contact was not actually in East London but in West London; an ex-student from my university put me in touch with Pakistani woman who had diabetes and arthritis. I went to interview her and we built up a close rapport. She invited me to rent the box room in her house and I spent February – December 2004 living with her. In Newham, where I had no existing contacts, I began by volunteering in community groups, which tended to be targeted at an overarching ‘Asian’ or ‘Muslim’ identity rather than at ‘Pakistanis’ or ‘Kashmiris’. Over a period

of two years, I attended six community groups on a weekly, fortnightly or monthly basis, which gave me sustained and regular contact with people and allowed me to gain their confidence. Getting to know people in the institutionalised setting of the community groups was a way to get to know people outside the groups, in their ordinary lives, and I developed fond and multiplex friendships with a small number of key individuals who became my four East London ‘fieldwork families’. One woman identified a member of her *biradari* from whom I rented a room in Newham from March 2005 – December 2006, during the most focussed period of fieldwork. The sustained contact with the ‘fieldwork families’ was invaluable in teaching me about the household process and the socio-cultural milieu of Newham, generating informal observational data with the intimacy that comes from participation in everyday routines.

Living and working in Newham was a chiaroscuro of mundane and bizarre predicaments. I taught English, designed more CVs than I can count, wrote successful job applications and letters to the Home Office, coached people for job interviews, helped with homework, picked children up from school, babysat and took them to swimming pools. I chipped in with domestic work, stayed over in people’s houses and talked till late at night. I accompanied people on visits to doctors’ surgeries, hospitals and walk-in-centres, and on outings to supermarkets, butchers, fabric shops and seamstresses. I went to cinemas and nightclubs, weddings, condolences and memorials, paid my respect in graveyards, sat in on *khatams* (Quran readings), attended the Milad-un-Nabee processions, Eid preparations and festivities, family visits and children’s birthday parties. I collected money for *kamatis* (credit associations) and attended job interviews and disciplinary hearings, meetings with social workers and lawyers, and immigration tribunals. I made observations in workplaces: staff rooms, grocery shops, takeaways and workshops. I got to know extended social networks of kin, friends and colleagues. I came to know one of the fieldwork families well enough to play “the *biradari* game”, which is a variant of “twenty questions” in which you have to take turns to guess members of the *biraderi* (extended family) instead of famous people. Another family named one of their goldfishes after me.

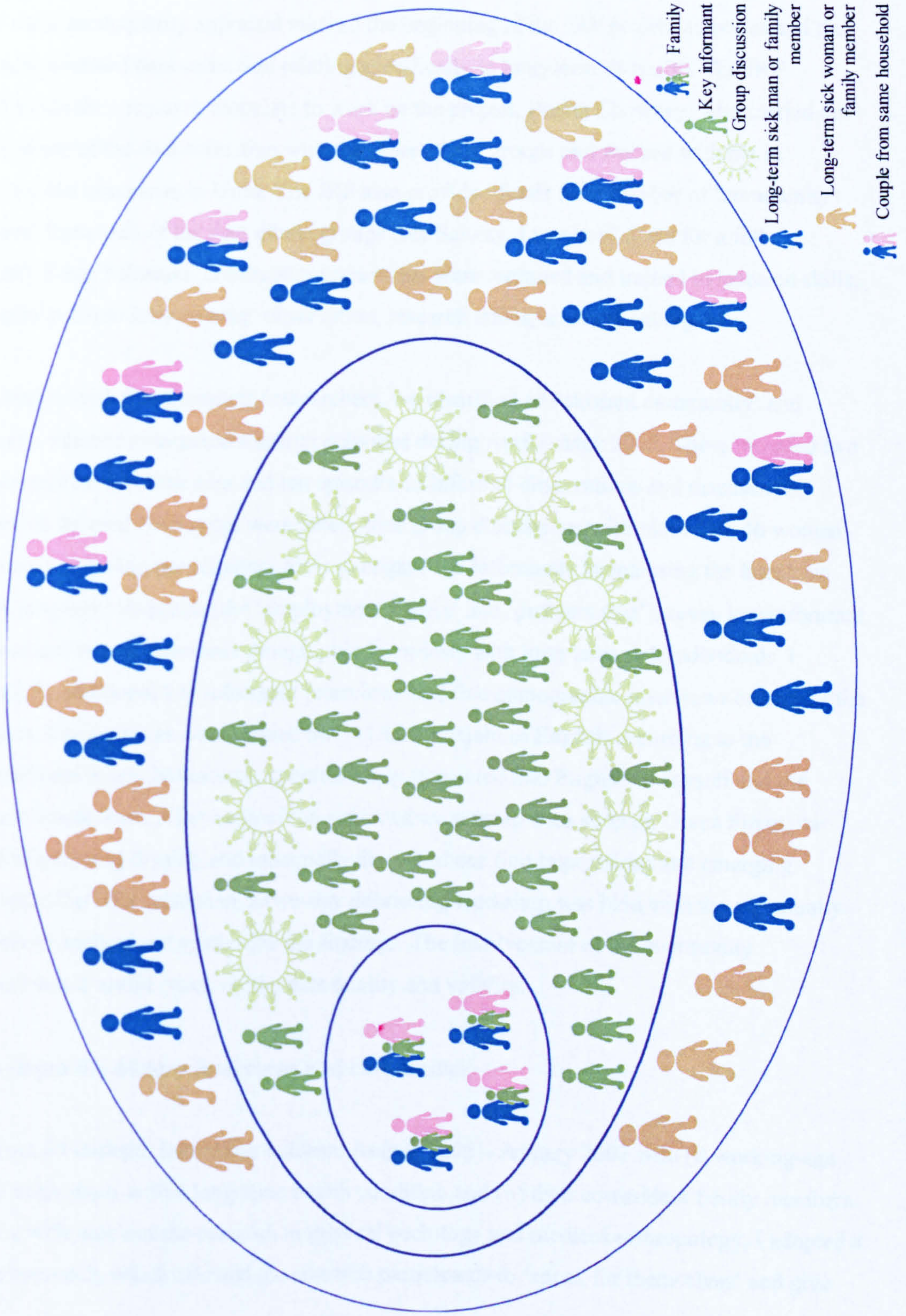
In the beginning I was constrained by my poor ability in Punjabi and Urdu, although language nonetheless opened doors of interaction with people who would otherwise have been inaccessible to me. With time and effort I improved, and it became easier for me to understand spontaneous interactions between Punjabi and Urdu speakers, as well as the more stilted language they used when speaking with me. My Urdu became better than my Punjabi, as the diversity of regional forms of Punjabi made it unsuitable as a lingua franca for working with Pakistanis. However,

Punjabi allowed me to connect with people on the basis of informal ties of home and family rather than Urdu, which was used in more formal settings. I wrote more than 600 pages of field-notes on the basis of 26 months of participant-observation. Although writing the field-notes was time-consuming, I value their breadth, and in retrospect I think that participant-observation provided the richest, most revealing and insightful data. It fostered thoughtfulness about “social life in the round, the appreciation of context and meaning, and the relational perspective” (Wallman 1984) (p.42). It allowed me to observe changes over time, and captured the complex, shifting and situational orientations that individuals had towards the place of long-term ill-health in their lives. Most importantly, it allowed me to make my own observations rather than rely on the accounts given in interviews. Whilst the interviews tended to generate data on the problems that individuals had surrounding long-term ill-health, participant-observation generated insights into their resilience, ingenuity and practical ability to garner resources and get by.

4.3.2. Pakistan

When research is focussed on people with extensive transnational connections, contextual depth is lacking when the focus is on single sites, and a more appropriate methodology is to pick up the connections and ‘follow the people’ (Marcus 1995; Gupta and Ferguson 1997). I managed to spend December 2004 – March 2005 in Pakistan on an overseas institutional visit sponsored by the ESRC, during which I did an internship with the Population Council and spent time with branches of families I knew from London, in Islamabad, Lahore, Karachi and Mirpur. Though brief, this phase of the research was very important to my later credibility and positionality in East London. It was also important in encouraging the informants to talk about the transnational dimensions of their lives, tapping onto the continuous flow of information, goods and people between Pakistan and the UK, and the involvement of transnational family in decision-making about the deployment of resources on both continents. The value of the transnational component of the research was in making me recognise that “migrants held and maintained relationships with people and places through practices that went beyond the model of Britain as the receiving context and the sub-continent as the sending context” (Mand 2005) (p.6).

Figure 4.2: Schematic diagram representing data sources and collection methods



4.3.3. Rapid participatory appraisal

Rapid participatory appraisal is a useful way to focus the type of insights gained from observational data in a more focused manner, although with much less depth (Rifkin 1996). The phase of rapid participatory appraisal marked the beginning of the JRF project activities and the more results-oriented data collection relating specifically to long-term ill-health. The JRF provided funds for a research associate to work on the project, Punita Chowbey, who carried out the lions' share of the data collection with the other ethnic groups and worked with me in carrying out the interviews in Urdu. The JRF also provided funds for a number of 'community researchers' from each of the four ethnic groups (see Salway, Levy et al. 2006 for a full discussion). Four 'Pakistani' community researchers were recruited and trained in research skills, including in in-depth interviewing, observation, research ethics, and note-taking.

In consultation with the community researchers, we identified a 'Pakistani community' and carried out a number of targeted research activities during April – May 2005. These included two purposive walks around the area and ten episodes of informal observations and discussions, during which detailed field-notes were taken; nine group discussions with more than 46 women and 15 men, employing participatory tools to engage the informants in analysing the knock-on effects of long-term ill-health (the 'employment matrix' and 'problem tree'); seven key informant interviews; and two open-ended ethnographic interviews with long-term sick individuals. I carried out 32 additional key informant interviews and five ethnographic interviews outside of the JRF project. The activities were carried out in Urdu, Punjabi or English according to the informants' preference. Notes were spontaneously translated into English by myself and the community researchers. After each of the activities we went to a tea shop on Green Street, the local Asian shopping district, and informally discussed our first impressions and emerging hypotheses. After data collection, a two-day debriefing workshop was held with the community researchers to analyse and synthesize the findings. The involvement of the community researchers was a useful check on the data quality and validity.

4.3.4. In-depth life-history interviews and case studies

I carried out 50 in-depth interviews between August 2005 – January 2007 with (i) working-age Pakistani individuals with a long-term health condition and (ii) their co-resident family members. In keeping with much of the research in medical sociology and medical anthropology, I adopted a narrative approach, which allowed the research participants to 'speak for themselves' and give

accounts that revealed how they made sense and meaning out of their experiences (Hydén 1997; Bury 2001). To focus the interviews on the livelihood impact of long-term ill-health, we developed a 'life-grid' method as a flexible guide to facilitate discussions about the clustering and inter-relationships between events in the life-course (Holland, Berney et al. 1999; Parry, Thomson et al. 1999). The informants began by describing their current state of health, then provided a history of the onset of the health condition and any major changes in their health over the subsequent years. As other life events were mentioned, they were marked down on the grid in rows representing different dimensions of peoples' lives (see p.101). A semi-structured list of prompt questions was designed and used to guide the discussions. The life-grid interview proved to be an excellent tool to structure the life-history interview around the consequences of long-term ill-health, as it tracked livelihood transitions in relation to changes in health status. I allowed the interview to be led by the informants as much as possible, which meant that they were able to discuss events from their own perspective. The interviews were rich and relatively long, lasting an average of two hours (ranging from one to four hours). I deepened specific lines of inquiry inductively as the research progressed, as I developed a more nuanced appreciation of the circumstances of long-term sick Pakistanis.

I purposively tried to identify a diverse sample of informants, to ensure the conceptual generalisability and comprehensiveness of the analyses. To ensure a wide range of predicaments, I used multiple recruitment strategies and points of contact. I began with institutional contacts, drawing on the relationships I had made through volunteering in community groups and extending out of the social networks of the community researchers. The rapid participatory appraisal had also generated a number of potential contacts and the project gained a momentum of its own. Table 4.1. summarizes the characteristics of the in-depth interviewees (p.102). I was somewhat more successful in accessing women than men. The data contained eight pairs of respondents in which long-term sick adults and family members were interviewed from the same household. The paired interviews serve as 'case studies', giving multiple perspectives about the phenomena being studied, allowing me to follow changes over time and reducing the bias from procedural reactivity (Hammersley 1992). They provided a deeper understanding of the dynamics of the household livelihoods and the context of long-term ill-health, and revealed fascinating differences in perspectives; the contradictions and convergences in the accounts given by the two household members allowed me to build up a much more holistic picture of what was going on in the household, and made the data in each of the individual interviews more meaningful. Ten interviews were carried out in Urdu or Punjabi. Translations into English were carried out by a small number of experienced translators with whom we were in close contact. The translators

were encouraged to transliterate resonant words and phrases in Urdu or Punjabi so as not to lose the idiomatic meanings.

Plate 6: Completed life grid.



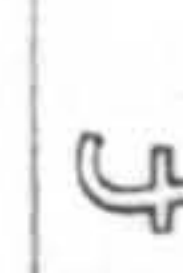

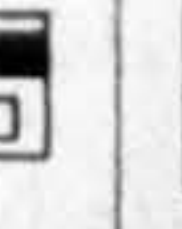
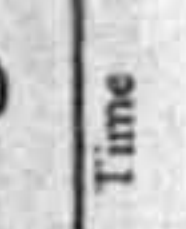



<p>Sufferer: ID 11 / KH / 13 P</p>	<p>COPIING - GOOD TIMES / BAD TIMES</p> 	<p>started going to gym - after lot of encouragement from family & friends</p> <p>A-4 hrs sewing course</p> <p>changed self completely</p>	<p>Nani had cancer - she was inspiration to us - 50 yrs in domestic violence partner has given me so much confidence</p>
<p>SUPPORT FROM SOCIAL SERVICES</p> 	<p>SUPPORT FROM FRIENDS, NEIGHBOURS, RELATIVES</p> 	<p>met long time family friend - started to take me out - she taught me how to dress up</p> <p>bhabi is good friend</p>	<p>dome nikahat all bits of marriage</p>
<p>SOCIALISING / LEISURE</p> 	<p>FINANCES / INCOME / EXPENDITURE</p> 	<p>wouldn't socialize hardly any friends - he scared we told me how ugly off</p> <p>he left £10,000 in just paid debts - paying his mortgage</p> <p>resented own children</p>	<p>remortgage - £10-15,000 back into account</p>
<p>FAMILY ROLES + RELATIONSHIPS</p> 	<p>WORK / EDUC / TRAINING</p> 	<p>aged 15 when had first daughter</p> <p>1995-9 - fam business</p> <p>1999 - he went bankrupt</p> <p>2000 - he went to sewing course at Shalom</p> <p>2002: he took me on as an admin</p> <p>2001: through friend - making changes to home, baby coming</p>	<p>Feb - court hearing about this loan - didn't want to be burden on bro + parents</p> <p>went to read + had job in first 3 hrs</p> <p>job @ warehouse</p> <p>left - depressed</p>
<p>WHERE LIVING + WITH WHO</p> 	<p>HEALTH SERVICES</p> 	<p>divorce 2001</p> <p>in own house since 2000</p>	<p>couldn't sleep</p> <p>no confidence</p> <p>would cry</p> <p>depression</p> <p>mental illness since</p> <p>stabbing</p> <p>asthma - cos of him</p>
<p>HOW YOU WERE FEELING / EMOTIONS</p>	<p>HOW YOU FEEL HEALTH WAS</p>	<p>parents sent me to study</p> <p>grandparents arranged marriage w/o stabbing</p> <p>15 yrs did</p>	<p>after have coughs</p> <p>pregnant - 4 wks preg</p> <p>he made me have an abortion 2001</p> <p>more m-h probs</p>
<p>Time</p>	<p>Aug/Sept 2005</p>	<p>16-18 - getting counselling</p> <p>mum looked after for 4m</p>	<p>feeling better</p> <p>always anaesthetic</p>

Table 4.1. Profile of long-term sick individuals and family members interviewed in-depth

	Long-term sick individual		Family member		Total
	Male	Female	Male	Female	
<i>Health condition of long-term sick individual *</i>					
Diabetes	5	9	4	4	22
Heart disease	4	2	-	1	7
Mental illness	4	6	2	3	15
Arthritis	1	3	1	-	5
Back/limb pain	4	2	2	-	8
Cancer	-	-	-	2	2
Other condition	8	10	5	5	28
<i>Age group</i>					
20-29 years	3	3	-	5	11
30-39 years	2	7	1	5	15
40-49 years	3	4	1	-	8
50-59 years	3	6	2	1	12
60 years +	4	-	1	-	5
<i>Marital status</i>					
Married	10	12	5	5	32
Div/separated	2	5	-	-	7
Widowed	1	1	-	1	3
Never married	2	2	-	4	8
<i>Employment status</i>					
Currently working	4	3	2	4	13
Worked in past	10	14	3	2	29
Never worked	1	3	-	4	8
<i>Interviewed in Urdu or Punjabi</i>					
	2	6	2	1	11
Total	15	20	5	10	50

* = Long-term health conditions were those reported by the informants, which may or may not have been explicitly diagnosed by a health professional. The number of conditions reported is greater than the number of respondents because individuals commonly reported more than one condition. 'Other conditions' included high blood pressure, glaucoma, kidney disease, stomach ulcers, gall stones, migraines, epilepsy, visual impairment, hearing conditions, skin diseases, complications arising from tuberculosis and polio, thyroid and gynaecological conditions. Many of the family members also had long-term health-conditions.

The life-history techniques were invaluable in capturing transitions in relation to long-term ill-health: it would have been impossible to observe these events taking place in real time. In allowing the informants to reflect back and voice their thoughts and feelings, the interviews also provided insights that contrasted surprisingly with the observational data. For instance, I observed Naseem to be a woman who was perpetually surrounded by friends and relatives, and an important decision-maker and dispenser of advice within her extended family. The idea that she might be lonely was far from my mind. However, during the interview she expressed that since her husband had died she felt that her social relationships had become a mere pretence. She felt unable to share her continued grief with her relatives and friends as they wished for her to get on

with her life and stop dwelling on his death. In retrospect, I think the most powerful insights were drawn from carrying out the observational data and the in-depth interviews side-by-side. They gave complementary behavioural and subjective perspectives, highlighting different aspects of experience. Moreover, where I had already built up a strong rapport with the informant, the interviews were more open and honest. As Umbreen reflected, “I felt easy talking with you because the last time you came you just sat and got to know me as a person and had a laugh with me – I did feel that you cared about me as a person rather than just bam bam bam with the questions like some of the therapists do”. The sustained contact with the informants also meant that I was able to capture the dynamism and diversity in their trajectories subsequent to the interviews.

4.3.5. Dissemination workshops

During March – May 2006 we organised two feedback workshops in Newham to share the emergent findings, which were produced as leaflets and translated into Urdu. They were intended to give the informants the possibility to ‘own’ or influence the ways in which they were represented. The workshops also provided a check on the data validity, although it would be misleading to suggest that the informants’ querying of the findings lead to substantial rewriting. Rather, I felt that ideologies and power relations within the community prevented the informants from being able to recognise the relevant dimensions of their situation. For example, some of the older men challenged the analysis of household roles and presented quite an essentialising overview of women carrying out “the household chores that traditional Pakistani women do”. Interestingly, the men’s discussions were in turn rebuffed by a young professional woman who objected to the generalisations they had made.

4.4. Operationalisation of key concepts

4.4.1. Long-term ill-health

We required that the informants should have an ongoing health condition and that the onset should have been during adult life. We used the terms ‘long-term health problem’, ‘long-term health condition’ and ‘long-term illness’ and gave examples of health conditions such as diabetes, heart disease or depression. In Urdu we used the rather literal and clumsy construction *lambe arse ki bimaree* (illness of long duration) as well as the more emic *mareez* (patient). In Mirpuri the community researchers chose to use the term *maande* (weak or frail). We did not specify any

precise degree of severity, duration or interference with daily activities. The approach allowed us to explore subjective interpretations of long-term ill-health and the extent to which the informants regarded themselves, and were regarded by others, as 'long-term sick'.

4.4.2. Ethnicity

My initial points of contact were community groups targeted at 'Asians' or 'Muslims', within which divisions by religion, country of origin and caste rapidly became apparent. Most of the informants identified strongly with the ethnic label of 'Pakistani' and referred to the category spontaneously in their own speech. However, the more emic formulation of Pakistani ethnicity were the more fluid *apne* (our own), *ham log* or *asaan log* (our people). *Apne* could have a variety of meanings in different contexts, sometimes referring to other Asians, Muslims, Pakistanis, Punjabis, Kashmiris, or other members of a single *biradari*. The informants also referred spontaneously to the concept of *hamara maashra* (our society), which was a fascinatingly polysemous term conveying the ways of life that prevailed among, and the behavioural expectations that were entailed by being *apne*. These concepts identified a group of people who were felt to be similar, with whom there was a possibility of community life, and over whom there were certain *haquq* (rights and expectations) including moral judgement. The Pakistani 'community' was therefore not delineated precisely, but remained a salient point of co-identification.

4.5. Data analysis

'Critical ethnography' involves synthesising the testimony and actions of informants with a broader historical and structural analysis. The final analysis is "not derived exclusively from the ethnographic data but from an oscillation between that and social critique" (Wainwright 1997) (p.12). I continued my readings throughout the analysis as new connections emerged and expanded my gaze. However, I tried to avoid imposing a priori theoretical constructs and 'ground' the analysis firmly in the data through ongoing sampling and analysis. Whilst in the field, I kept a folder of threads to follow up on and emergent hypotheses to which I added when inspired to do so. After completing the in-depth interviews I made notes to remind myself about aspects of the interview process that would not be recorded in the transcript. I transcribed most of the interviews myself, which familiarised me with the content and imprinted the tone and delivery of the 'text' of the interview firmly onto my memory. It also encouraged me to reflect more deeply on the emotion and content of the interviews; gaps, missed opportunities for questions,

and ambivalences. Whilst carrying out the interview I was only able to process a small part of the intriguing detail that the transcripts revealed when I inspected them more closely.

The interviews that contributed to the JRF project were analysed using the software package Nvivo. However, although the process of applying the codes to the data was useful for becoming familiar with the content of the interviews, I was dissatisfied with Nvivo as I found that the disembodied chunks of text it retrieved were misleading when abstracted from the rest of the narrative, failing to capture the important contradictions within the interviews. For the main data analysis for this thesis I adopted 'framework analysis' (Ritchie and Spencer 1994). I found that framework analysis was better at integrating the need to break down the data and pull out cross-cutting themes with the need to analyse on a case-by-case basis. The integrity of the informants' accounts was preserved throughout the analysis, which was important in capturing the multiple perspectives and internal inconsistencies contained within the interviews.

1. Familiarisation: a full review of field-notes, recordings and transcripts.
2. Thematic analysis (the 'framework'): themes from initial analysis were developed into a coding scheme, which was organised into five separate 'tables' (i.e. Word files): (i) long-term ill-health; (ii) getting by; (iii) everyday reproduction; (iv) inter-generational reproduction; (v) inter-household arena; and (vi) community history.
3. Indexing: applying the themes systematically to the text of notes and interviews.
4. Charting: using headings and sub-headings to rearrange the data by theme or by case, to give a picture of the data as a whole, both across cases and under themes.
5. Mapping and interpretation: clarifying associations and inter-connections.

4.5.1. Analytic sets

Writing-up presented the challenges of turning individuals into sources of data, capturing the diversity of the sample and their obdurate resistance to generalisation. I decided to employ the device of contrasting 'analytic sets' of individuals who were in similar circumstances, which allows fluid and varied life histories to be combined with a degree of conceptual focus (Ball, Maguire et al. 2000). The names for the sets are 'in-vivo categories' inspired by Kalra's work on the labour experiences of Pakistanis in Oldham (Kalra 2000). They are evocative when used in the field, and they direct attention to patterns of similarity and difference by virtue of migration histories, gender and age. Kalra's categories are based on the labour experiences of Pakistani men:

- I. **Babas:** elder men – *baba* is an honorific term for an elder male in Urdu and Punjabi, sometimes used as a suffix to the name of a widely known and respected elder. The Babas were brought up and educated in Pakistan and came to the UK in the 1960s as labour migrants. They tend to have strong attachments to Pakistan.
- II. **Kakas:** their sons – *kaka* means son or boy. Kakas usually came to the UK as children and received some schooling in Pakistan before migrating under the charge of their fathers or uncles. They have lesser attachments to Pakistan than the Babas but share their labour experiences in industry and the shift to self-employment.
- III. **Mangetars:** marriage migrants – *mangetar* means fiancé. The *mangetars* straddle the older and younger generations. They tend to be in a weaker position due to their Pakistani qualifications and poorer access to kin networks in the UK.
- IV. **Lads:** young British-born men – the Lads are British-born and educated. Unlike in Kalra's study, the Lads in Newham are positioned diversely in the labour market, and not uniformly marginalised in employment or in relation to older men.

In addition to Kalra's categories I have added a further, largely male category:

- V. **Freshies:** new labour migrants – Freshies are legal or illegal new migrants who have come to Britain as students, skilled or unskilled workers and asylum seekers. They tend to be in an even weaker position than the Mangetars due to the insecurity of their immigration status, restrictions on employment and lack of welfare entitlements. They are a salient and provocative presence in Newham.

Kalra only has one female category of 'women', but acknowledges that this category requires more exploration in order to map an accurate picture of the predicaments of Pakistani women. I suggest my own set of 'in-vivo categories' to examine the situations of women:

- VI. **Valdas:** elder women – *valda* means 'mother' in Urdu and Punjabi. Valdas are Pakistan-born and Pakistan-educated and mostly marriage migrants who joined their husbands in the UK in the 1970s and 1980s. Many were economically active in the early years after migration. They tend to have strong attachments to Pakistan.
- VII. **Udher ki:** Pakistan-born women – *udher ki* means 'from there' in Urdu. Udher ki are younger marriage migrants who married the Kakas and Lads and are not yet at the apex of their families, usually still being the daughters-in-law of the Valdas.

VIII. **Idher ki:** British-born women – *idher ki* means ‘from here’ in Urdu. Idher ki are British-born and educated and like their male counterparts, are positioned diversely in relation to the labour market and in their relations with older women.

The ‘analytic sets’ highlight common life experiences but are not mutually exclusive, and the allocation of individuals to the sets is not simple or absolute. The device has weaknesses as well as strengths, as it potentially runs the risk of overly fixing or stereotyping individuals within these groups. However, I would argue that the groupings are useful as a heuristic device to identify individuals with similar experiences without overly essentialising the informants.

4.5.2. Assumptions about the data

Mason points out the importance of being clear on the ontological and epistemological position of qualitative analysis, namely “what is the nature of the phenomena, or entities, or social ‘reality’” (Mason 1996) (p.11) and “what might represent knowledge or evidence of the entities or social ‘reality’” investigated (*ibid.* p.13). Evidently, the epistemological status of reports of behaviour is problematic. Several interviews with mentally ill informants made me seriously question the ‘reality’ of the narratives and served as poignant reminders of the constructed nature of the ‘realities’ presented in the interview. Silverman asks provocatively: “it simply makes no sense to argue that all knowledge and feelings are of equal weight and value. Even in real everyday life, we sort ‘fact’ from ‘fancy’. Why, therefore, should science be any different?” (Silverman 1998) (p.111). In such cases, observational data and paired interviews, if any were available, allowed me to triangulate the particularly problematic accounts, offering alternative perspectives which allowed me to be more confident about the validity of the narratives.

In presenting the data in the thesis I have relied mostly on quotations from the in-depth interviews. This gives a flavour of how the informants constructed their own ‘local worlds’ and gives the reader a basis on which to interrogate my analysis. Moreover, I have ethical concerns about using the observational data in the thesis as the ‘fieldwork families’ and many of the individuals I met in Newham became close friends as well as informants, and my role as a researcher often receded from the imagination. The material in the in-depth interviews was collected formally and the researcher role was explicit and unforgettable, so I do not have the same reservations over the use of the material. However, the analysis draws on insights generated from all of the various research activities and often, when a point is too complex to be illustrated

through a tidy quotation, I have presented direct observations or sketched out the informants' predicaments instead.

4.5.3. Validity

Validity in qualitative research is the extent to which an account accurately represents the social phenomena to which it refers (Hammersley 1990). The validity of the qualitative study rests partly on the theoretical comprehensiveness of the sampling and partly on the ways in which I have interrogated the data (Green and Thorogood 2004). Beyond this, there are inevitable questions concerning the potential for the research process to affect the behaviour of informants in ways that threaten the validity of the findings. The interviews were inevitably prone to self-presentational biases. The narrative method produced a tendency for self-pity and victimisation and a particular type of abstract, disembodied talk concerned with psychological process rather than "conveying the mundane aspects of experience" (Bury 2001) (p.283). The interviews with women were particularly self-victimising. The pressures on women to 'suffer in silence' and endure ill-health and misfortune without complaint, as I discuss in Chapter 4, meant that many of the women apparently had little outlet for discussing their health conditions. The interviews were often tearful, and many of the women said that they had never talked about their personal tragedies openly with anybody in their lives; "I think this is the first time I've ever talked to anybody openly about this. Maybe because I don't know you, you're outsiders to me, and I feel safer"; "I'm talking to you, these are things that I probably haven't even said to anyone in my life". The interview context seemed to elicit 'emotional performances': "what kind of women have harder lives than me? You talk to a lot of women – who has lived through the most?". As Grima shows, such performances are bound up in Pakistani constructions of feminine ideals (Grima 1992; 2002). It was therefore important to 'triangulate' the interview data and examine the different versions of the 'truth' that were given by different individuals in different contexts by situating the interviews alongside the observational data and paired interviews. Furthermore, the sustained contact that I had with the informants allowed me to witness shifts in interpretations of the same events, and access private as well as public explanations. The nonsensical employment history that Faisal gave in his interview, for example, became understandable when he later informed me that he had spent five years in prison: he chose not to disclose this in the interview. However, I think that in general the emotional intimacy and spontaneous volunteering of sensitive information in the interviews suggest that in many cases they did genuinely tap on to the informants' subjective constructions of events.

My own positionality also potentially impacted on the behaviour of the informants in ways which threaten the validity of the findings. As a White, middle-class, unmarried, young and female researcher, my personal characteristics have undoubtedly influenced the study. According to opinion, my multiple differences to the informants can be seen as either detrimental or advantageous to the research process. Kanaaneh stresses the greater perceptiveness of 'indigenous' researchers and the additional intimacy that they may introduce into their accounts (Kanaaneh 1997). By contrast, Hammersley and Atkinson argue that suspending preconceptions may be more difficult for a researcher working within their own society as they may not be able to take the 'novice' role, which aids learning, and it may be more difficult to suspend 'commonsense' assumptions about the 'obvious' (Hammersley and Atkinson 1995). In practice, I felt that my positionality veered erratically between insider and outsider in the field. At times I was trusted with private jokes, local knowledge, and delicate revelations; at other times I was aware of how unnatural and unsettling my presence might be. To Punita, the research associate, an informant asked for reassurance about my motives after I left the room – "this isn't about the bombings, it isn't going to make the Muslims look bad, is it?". A man fluent in English switched to Punjabi to voice suspicions about me working as an undercover government agent. It is pertinent to note that the period of fieldwork coincided with the July 7th bombings and the Forest Gate shooting. Even the relationships with my closest friends were laced with uncomfortable assumptions, close-to-the-bone questions and humour. I presented an unusually intimate link and interface with White society; a threat as well as an opportunity.

For me, the important considerations were that I should be aware of how the shared understandings and misunderstandings resulting from the multiple identities of myself and the other researchers might affect the research interactions; connections and disconnections as women, men, older, younger, married, unmarried, Indian, Pakistani, English, Hindu, Muslim and presumed Christian; and be aware of the assumptions I was making, alongside the assumptions of those whom I was researching. For example, the fact that I am not a Pakistani Muslim is almost certainly responsible for the informants' tendency to explain their situations in terms of 'our culture' and 'our religion'.

4.6. Ethical considerations

Ethical clearance was granted by the LSHTM ethics committee on the grounds that the research would be scientific and rigorous; collected on an informed and voluntary basis; the informants' confidentiality and anonymity would be respected; they would not be harmed during data

collection; they would be provided with feedback after data collection; and that the findings would be disseminated to relevant agencies. The ongoing findings were disseminated to the partner NGO Social Action for Health for use in their projects on self-management and benefits advice, and two large events were eventually held via the JRF project with central government and the national voluntary sector in May and June 2007.

In practice, the thorniest issue was negotiating informed consent during participant-observation. The informants were aware of what I was doing and that I was interested in learning about the experiences and consequences of long-term ill-health among Pakistanis for the purposes of my PhD. However, I developed relationships outside the immediate concerns of the research with many individuals, and although it was important to my own understandings and contributed to the development of the inquiry, much of the data was so informal that it would not have been ethical to write it up in specific terms. The issue of who gave me informed consent was also problematic; some members of families and community groups were happy to be part of a research process, and others were not. In one family, people said that it was “really cool” that I took notes of things they said, and volunteered abundant information without me asking, inviting me to carry out additional research activities such as drawing family trees. On the other hand, in the house in West London, a second lodger who moved in three months after me was distinctly unhappy about me observing and participating in Pakistani domesticity. She didn’t like me asking questions, and let me know that certain topics were strictly off bounds: “this is about our religion, you won’t understand”. I tried to be sensitive to these dynamics by respecting people’s objections and writing my field-notes selectively.

The second very thorny issue was that of the ethics of representation. The prolonged contact I had with the informants and the relationships of confidence that developed meant that I was complicit to data on informal and sometimes illegal economic activities – not only in the course of participant-observation but also in the formal interviews. Hobbs argues that the principal contribution of ethnographic research is in improving our understanding of social phenomena, and that researchers should not be shy of uncovering and discussing illegality if the richness and depth of the data are considered at all important (Hobbs 1988). However, the pitfalls of misrepresenting the research subjects in the course of revealing problematic material have been widely discussed in the literature (see Scheper-Hughes 2000). I have tried to be sensitive to the interests of the informants by editing out some of the more salacious findings. As the same time, I did not want to write a thesis that was misleading or dishonest, so some of the discussions remain. To protect identities, all the names and identifiable details in the thesis have been changed.

4.7. Limitations of the qualitative component

The flexible and inductive nature of the qualitative component of the research means that it touched upon a number of areas which need to be unpacked by further research:

- I. The **informal economy** of the East End was an important backdrop to the research, and the thesis provided glimpses of the pervasive economic opportunities upon which people could draw from this undocumented economy. However, more systematic research on the informal economy needs to be carried out to understand its causes, dynamics and impact upon the livelihoods of local people.
- II. Co-ethnic ties emerged from the fieldwork as very important in mediating claims to employment. The fieldwork also suggested that co-ethnic ties may influence on job retention. However, further research is needed on **how ethnicity mediates the social relations of work**, particularly the relations between employers and employees, patrons and clients, and the impact that this has on job security.
- III. The informants were well aware of media discourses on health and social inequalities and that Pakistanis were viewed as a problematic group: deprived, disadvantaged, politically marginalised, and possibly also religious fanatics. As I outline, the informants resisted the deleterious moral consequences of long-term ill-health and poverty in a variety of ways. However, more research is needed on the **impact of deprivationist discourses** on the subjectivities of individuals belonging to marked groups (see Imtiaz 2002).
- IV. The informants were quick to essentialise family forms and point out areas of contrast with White culture. However, in reality family forms were hugely diverse. A number of the households in the fieldwork were dealing with long-term ill-health in the context of already strained and conflictual marital relationships, or in complex reconstituted families. Systematic research to explore the emotional and structural dynamics of **marital instability and divorce**, the contradictory flows of love and enmity in reconstituted families, the gendered impact on the moral status of family members, and the resources that can be accessed by divorced or separated individuals through their social ties.
- V. **Transnationalism** emerged from the fieldwork as playing an important role in the response to long-term ill-health. The impoverishment engendered by ill-health required the informants to mobilise any transnational assets they had; transnational kin migrated for the purposes of providing care; ill-health in the Pakistani branches of transnational families were an additional financial strain for households in the UK, and a cause of flows of money and individuals

between the two countries. Also, ill-health often required a shift in transnational identities as it made travel or moving more difficult. A more systematic multi-sited ethnography is required to examine the dynamics in the sending areas with equal depth.

Chapter 5: Long-term ill-health

sabar ka phal meetha hota hai

the fruit of patience is sweet – Urdu saying

5.1. Introduction

This chapter leads on from the quantitative analysis, which demonstrated a high prevalence of ill-health and clustering of long-term sick individuals within Pakistani households. It begins the qualitative component of the study with an exploration of the social process of becoming long-term sick and the multifaceted expression of ill-health. In doing so, it sets the ground for the subsequent chapters examining the economic consequences of long-term ill-health.

The chapter draws on the concept of the sick role, which offers analytical purchase over the *practical* consequences of ill-health for individuals. As I discussed in Chapter 1, the sick role concept (Parsons 1951) has been criticised by the thrust of the chronic illness sociology for its excessive portrayal of long-term sick people as dependent (see Bury 1982; Charmaz 1983; Williams 1984; Bury 1988; Gerhardt 1990; Bury 1991; Carricaburu and Pierret 1995; Charmaz 2000; Pierret 2003). In contrast to the latter literature, however, the accounts presented here suggest that ambivalence towards and struggles over access to the privileges entailed by the sick role are a prominent part of the experience of long-term ill-health. As the Crossleys point out, “many individuals find themselves in a contradictory position where they embrace some aspects of *both* the empowerment and sick role discourses, fighting against the sick role whilst simultaneously being reliant on it” (Crossley and Crossley 1998) (p.159). The data here suggest that this is particularly the case where the power differentials between the individual and others in their local worlds are marked, as they were for many of the informants.

Most of the informants inhabited a liminal zone between subjectively experienced ‘illness’ and ‘disease’, as defined by experts and health professionals. Some had been diagnosed with specific health conditions; others had not, and remained in ‘diagnostic limbo’, seeking ‘permission to be ill’ or ‘striving for the sick role’ (Dumit 2006; Nettleton 2006). As Glenton points out, in the case of long-term health conditions the professional’s inability to offer a clear diagnosis, explanation and course of treatment does not necessarily make them redundant; it can also increase and prolong the patient’s dependence on them (Glenton 2003). The informants also inhabited a liminal zone between being ‘diseased’ in the eyes of medicine and being seen as ‘sick people’ in

the eyes of significant others in their immediate worlds. On the one hand, the sick role brought recognition of their loss of capacities and need for assistance. On the other hand, it brought social abnormality and stigma – interactions with other people came to be informed by their deviance rather than their whole personality (Goffman 1963). Although the processes of resisting ill-health and gaining control of the health condition were certainly evident in the accounts given by the Pakistani informants, the sick role was also very relevant to their experiences. Long-term ill-health simply led to: “a different and perhaps more complicated way of being sick. It requires a different, longer-lasting and more demanding cultural performance” (Frankenberg 1986) (p.624).

In understanding the social process of becoming long-term sick, it is important to focus on “the implications for social relations in general” (Frankenberg 1986) (p.606) and “the systematic correlation between economy, polity and ideology, and performance in social encounters” (*ibid.* p.613). To capture these dynamics, following Kleinman and colleagues, I suggest that it is useful to see long-term ill-health as having a ‘social course’ determined by communications, negotiations and engagements in ‘local worlds of experience’ such as the home and community (Kleinman and Ware 1992; Kleinman, Wang et al. 1995; Hicks, Kleinman et al. 1998; Hicks and Lam 1999; Ware 1999). Within these ‘local worlds’ access to or resistance to the sick role is mediated by structural arrangements of power (Kleinman and Kleinman 1985). As I discussed in Chapter 1, the relevance of ethnicity is considered throughout the chapter through a structure-agency dynamic conceived in terms of social practice, which knits together interacting material and cultural factors.

5.2. Meanings of ill-health

The state of being long-term sick (a *mareez* or “patient”) came when it was recognised that a health condition was “not going to go away”. Long-term ill-health meant long-term dependency on medication and protracted interaction with health professionals: “this is something that I'm going to have to learn to live with”; “I'm going to have to do like this forever now” ; “there is no cure for that... you have to stick on the tablets”. The informants had come to experience their bodies through the lens of medicine. Long-term ill-health was understood as the insidious “tell-tale signs” of the “wear and tear” of the body as a result of cumulative assaults on the body and the self. It was bound up in ‘premature ageing’ (Pollen 2002); the informants felt and were seen to be growing “old before their time” in body and soul. For some of the informants, everyday life had become a *memento mori*, a constant reminder of the reality of their health condition and the finiteness of their existence. Long-term ill-health was also understood as closeness to death, and

many felt they had been given a new lease of life which was now full of meaning and potency. Liaqat, for example, could barely articulate his anxiety over the decline in his wife Nasreen's health: "it's killing disease you know, slowly slowly dying, diabetes...". Amina often cried about how she had nearly died during an operation on her heart; her husband had even bought the tickets to take her body back to Pakistan for burial. "It was taste like a death when I was in hospital... God give me other life, second life".

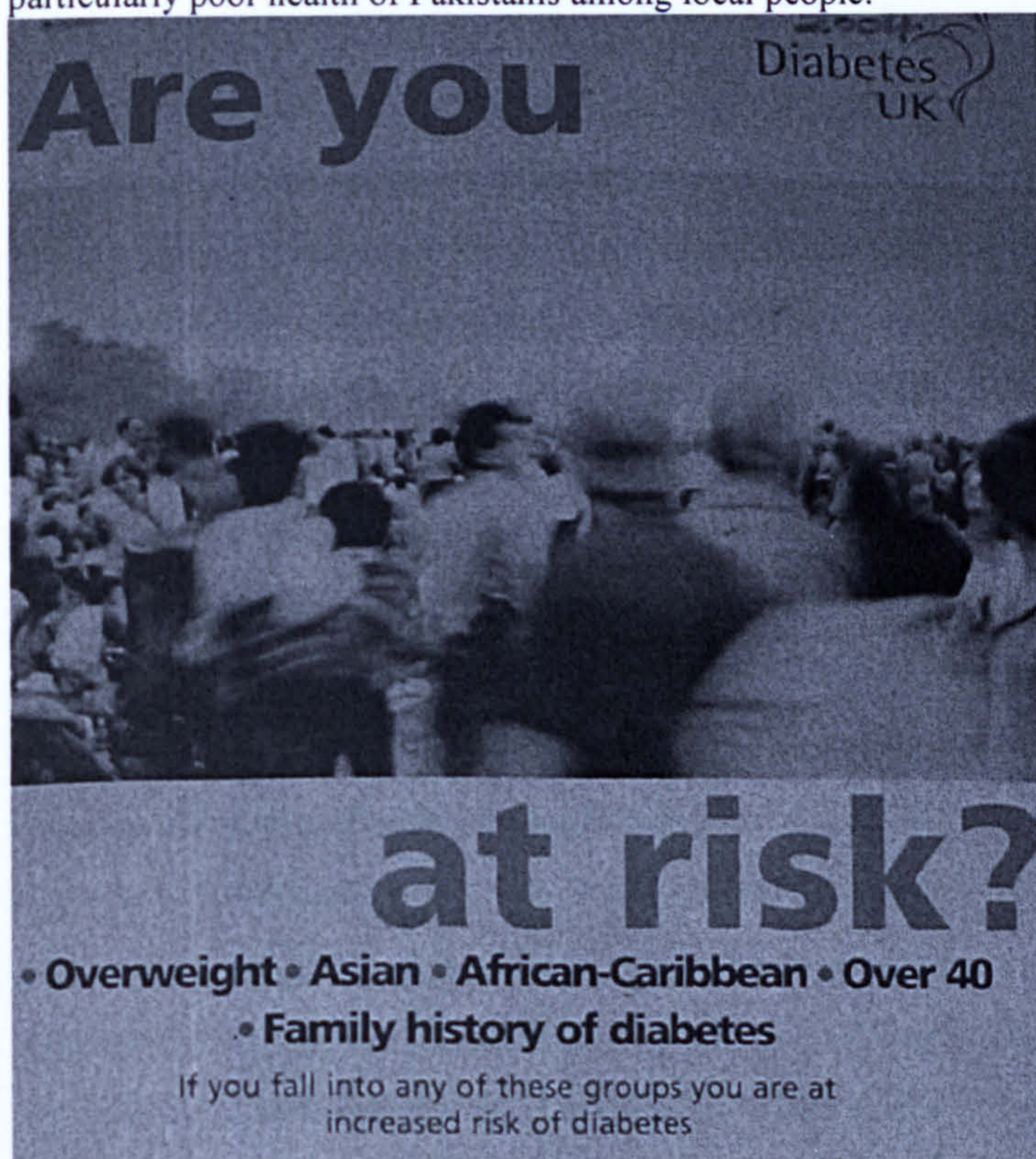
5.2.1. Explanations of ill-health

In line with the findings of Chapter 3, the informants noticed that long-term ill-health was particularly prevalent in the Pakistani community compared with others. Interestingly, the relative commonness and normalcy of long-term health conditions seemed to lessen the disruption they caused to individual biographies. Diabetes and heart disease were less threatening and stigmatising than other conditions because of their relatively high prevalence. As Faisal said, "diabetes you can control it well, everybody got it, and you can still live with it". Safia felt much the same: "everyone was like oh... nowadays everybody's a diabetic. But it's alright, it doesn't matter, try not to worry yourself too much".

People with long-term ill-health had often been diagnosed with more than one condition, in line with epidemiological research indicating a greater prevalence of comorbidity among Pakistanis than their White British counterparts (Greenhalgh 1997). The cluster of related conditions comprising diabetes, high blood pressure, heart disease and stroke were frequently concurrent in individuals and understood to be related to obesity, inactivity and the "Asian diet". Many of the informants had internalised the idea that "Asian food" was "bad for you" (see Bradby 1997; Jamal 1998) and guilty associated it with irresponsible health management. Heart disease, diabetes and hypertension were understood to be brought on by *motappa* (obesity) arising from the "richness" of the "Asian diet". Its oil, sugar, salt, chillis and spices were felt to be fine in Pakistan because the climate was hot and humid and the work was physical, but made the food too "hard" or "strong" to be digested in the UK, where the climate was too mild and the work was less strenuous (see Lambert and Sevak 1996; Chowdhury, Helman et al. 2000). Despite the importance of socio-economic differentiation in explaining ethnic inequalities in health, the informants understood the high prevalence of ill-health among Pakistanis in terms of cultural differences from the White majority, such as diet, rather than in terms of class differences; this is in keeping with other work showing that people from deprived backgrounds do not acknowledge the effects of socio-economic deprivation on health (see Blaxter 1997; Muntaner, Nagoshi et al.

2001; Popay, Bennet et al. 2003; Macintyre, MacKay et al. 2005; Davidson, Kitzinger et al. 2006).

Plate 7: Diabetes health promotion advert from a community centre in Stratford, 2004. The poster warns that Asian and Afro-Caribbean people are particularly at risk of diabetes, raising awareness about the particularly poor health of Pakistanis among local people.



Source: author's own.

In the accounts, mind, body and local world were connected through an overarching discourse of “stress”, which was the single most general, pervasive and multi-layered idiom that the informants used for talking about suffering. They drew upon “stress” as a medicalising discourse and believed that it triggered or exacerbated a number of long-term conditions including asthma attacks, hypertension, stroke, diabetes, heart disease, cancer and mental illnesses like depression, anxiety and panic attacks. Stress-related ill-health was seen as inherent in the *mahaul* (environment) of “modern” life and particularly characterised the busy, lonely lifestyles of the “West”, which were contrasted with an idealised, balanced, nurturing, wholesome way of life left behind in Pakistan (even by the Lads and Idher ki, who had never lived there). Interestingly, the medicalising explanatory model of stress-related illness seemed to be strongly shared with health professionals. Mumtaz’s GP, for example, told her not to try and find work as she would not be able to cope with the stress and it would make her “more ill”. The similarities between the

informants' and health professionals' understandings about the origins of their ill-health illustrates the embeddedness of biomedicine in the informants' lives and suggests the growth of 'lay expertise' (Prior 2003).

5.2.2. Preoccupation with ill-health

The informants showed differing degrees of preoccupation and engulfment in the ill-health. Preoccupation was related to the disease course and the psychological process of "getting on with it". In general, intense preoccupation with ill-health characterised the immediate aftermath of the health condition, after which many of the informants entered a process of "coming to terms with" their health condition, and the level of engulfment gradually declined. Safia recommended that there's "no point making a song and dance about it... just forget about the fact that you're a diabetic!". Yasin claimed that nowadays "I'm very chilled out... I've got over that now". However, this robustness did not develop in every case, and the informants' accounts and performances of resilience hinted at a continued internal struggle.

Preoccupation was determined neither by the individual disease course alone, nor by the clinical severity of the health conditions. Some individuals generally faced their health conditions with more robustness than others. Ubaid, for instance, was quite overwhelmed by his diabetes, whereas Faisal seemed little affected by his, even though he had to inject insulin and Ubaid was on tablets. An individual's level of preoccupation with ill-health also varied according to context. Subjectively, the informants often wanted to forget about and ignore their health conditions. They took creative steps to remain "normal" and resist internalising an identity as a *mareez* (patient). Although it was painful, Yasin forced himself to perform his five times daily *namaz* through the normal standing, bending and kneeling positions rather than reading his prayers from a chair, as he was permitted to do: "something inside me won't let me do it"; "I feel now with my back problem, you know, it's just me and this damn back problem, and I've got to beat it, I aint gonna let it get me down". Mumtaz showed me some books she had taken out from the library which were titled 'overcoming depression' and '1000 stories that can change your life for the better'. She was actively trying to understand and take control over her depression. She was adamant that "feeling sorry for yourself I think that is a total waste of your life"; "I believe in not giving up and just lying down all the time".

At the same time, however, the sick role also beckoned. Both Yasin and Mumtaz complained about other people expecting too much of them and failing to appreciate their difficulties and

reduced capacities. Mumtaz was proud that she managed to conceal her ill-health as much as she did, but simultaneously wished for it to be recognised properly by her family: “[my body] may be beautiful packaged outside but inside the contents, like my inner inside... Sometimes I have pain in my lungs, but nobody seems to be bothered”. The complex contradictions in the accounts reflected the fact that many of the informants were at heart ambivalent towards the place of their health conditions in their lives. Whilst they desired ‘normality’ and wanted to be “strong”, and “overcome” their ill-health, they also sometimes wanted to have recourse to the rights and obligations of the sick role – albeit on their own terms.

The informants’ preoccupation with their ill-health was linked dynamically to their wider predicament. The intensity of their symptoms waxed and waned in relation to “stress”; other “things going on” in their lives. The symptoms of Naila’s depression and diabetes, for example, rose and fell in response to tensions in her relationship with her now estranged husband: “when he makes me upset then my sugar goes”. The experience of ill-health and attendant stress was not necessarily the biggest problem in the informants’ lives. Perversely, for some of the informants the background of “things going on” in their lives could lend a degree of psychological robustness, as the significance of long-term ill-health faded in comparison with all the other problems they had to deal with: it was not their key concern or priority. For Ayesha and her mother, the violence of Ayesha’s stabbing in Pakistan overwhelmed the more insidious reality of the depression that followed it.

For many, the context of poverty and hardship made it impossible to be too preoccupied with ill-health. There was an imperative to remain economically active; they could literally not afford to be sick. Zulfikar was less bothered by his heart condition than by the fact that he had not been able to pay off his loans or make sufficient savings to build a house in Pakistan, and continued manual work until his early 70s despite deteriorating health. The persistent cough, chest pains and accelerating weight loss of Chotoo’s advancing tuberculosis were less urgent than his fear of the immigration authorities and the onerous imperative to return the £10,000 loan he had taken to pay an agent to bring him to the UK. By the time he was dragged to the GP by a concerned friend he was “nothing but skin and bones”, unwilling to seek medical care due to his anxieties about detection and the pressure to stay at work. Many of the informants were dealing simultaneously with financial and caring responsibilities for family members in Pakistan as well as the UK, and for some, problems connected to their status as new migrants. The accounts resonate with Erb and Harriss-White’s work on disability in South India, showing that socio-economic status conditioned the degree of disability that must be endured before a person could contemplate their

state of health and step into the full social role of being a disabled person (Erb and Harriss-White 2002).

Equally, rather than bringing a degree of robustness, long-term ill-health could also make people *more* vulnerable to stress, as it complicated and was in turn complicated by these other problems. Shaheen admitted that nowadays even small things were making her feel stressed: “I feel like somebody who thinks they’re ill all the time... I’ve got to the stage where I think everything is affecting me now. And maybe it’s not, maybe that’s what’s helping me bring the stress on even more”. Financial hardship was a key source of stress that affected the experience of ill-health and made it harder for the informants to manoeuvre within and manage any one of their other problems. Ubaid’s diabetes, for example, “flared up” and expressed itself as dark mood swings whenever the bills came in: “when you have to come down a few notches, things like, you know, even the bills can affect you... it just becomes a little bit overwhelming sometimes”. For others of the working-class informants, therefore, the context of poverty and hardship deepened the preoccupation with ill-health.

Individuals who attributed the origins of ill-health to events beyond their control, such as having had tough childhoods or tense family relationships, identified stress as particularly intractable. This was common in the accounts of women and subordinate-status men, reflecting their relative powerlessness. For example, Umbreen, already dealing with sexual abuse, profound mental illness and bereavement, was totally bowled over when she lost her house as the result of financial trickery; shortly afterwards, her husband was injured in an unprovoked attack that left him disabled and unable to work. “We just went downhill”; “I think this is the thing that has all my life stopped me from doing anything or... it’s like holding you back and feeling... I think it’s like feeling terrified”. Their household was decimated by the deluge of multiple, random, unfair problems that beleaguered them; their vulnerability to stress reflected the precarious balance of the order in their lives.

5.3. Diagnosis and interactions with health professionals

For the informants, the consensus of experts and health professionals was central to making their subjective ill-health socially meaningful; it was the process of diagnosis that legitimated the following period of sickness. Diagnosis was often actively sought out by the informants. After they became aware that their bodily or emotional states were “not normal”, until they knew what they positively “had”, they were in a restless, liminal state of being neither well nor sick. There

was often an element of relief and release when a disease was diagnosed, confirming subjective experiences of non-normality that had been indeterminate, sometimes for prolonged periods of time. Diagnosis provided individuals and family members with the hope of treatment and a potential release from suffering. It provided new routines of medications and lifestyle recommendations. Managing long-term ill-health became a new way of life through which individuals and family members re-constituted a sense of normality through everyday routines. After Bashir's diabetes was diagnosed, for example, he was able to get down to the everyday business of managing his health, and the inner conflict and uncertainty stopped. He was content with the words of encouragement he got from his GP, his dietician and the diabetes team in the hospital, who reassured him that his blood sugars were stable and his lifestyle was ok. "They say oh you are doing alright. I check my blood here at home. Sometimes I go 6,7,8 not more than that. But mostly that is 5,6,7. The most thing is you check your diet, what you eating there. But that's it. I am well controlled now".

Certain individuals like Bashir seemed to have a magic touch. There was something in their manner or disposition that meant that health professionals would be "friendly" with them, pleasant, respectful and cooperative. There were some individuals whose experiences were positive: "they are so good"; "believe me, I can never explain that how much they look after me". A positive orientation towards the health services was also sometimes couched in comparison with Pakistan: "this country has saved me; if I was over there I would have died". From the accounts, however, unproblematic diagnosis and treatment seemed to be relatively few and far between. The accounts suggested two main reasons for the problematic experiences of diagnosis: (i) the informants' powerlessness and marginalisation in relation to state healthcare; and (ii) the discrepancy between biomedicine and the informants' subjective experiences and presentations of ill-health. When diagnoses and treatments were delayed, the period of uncertainty about the nature, meaning and prognosis of the ill-health dragged on, and the informants became more preoccupied with their health; their lives were put on hold and it became harder for them to "get on with it".

5.3.1. NHS healthcare

In nearly half the cases, the sick person was said to have been initially unable to secure a positive diagnosis from their GPs or hospital doctors. In part, this is in keeping with research that has documented poorer access to certain health services and poorer quality of state healthcare for ethnic minority groups (Aspinall and Jacobson 2004; Commission for Health Improvement

2004). Many of the informants related that their diagnoses had come late, at a stage by which the health condition had become entrenched and irreparable. Time again, the informants complained of not being taken seriously by health professionals, who had the authority to dismiss their presentations of illness and make them feel illegitimate in seeking healthcare. A common theme was that of being told that the symptoms were not abnormal and that they were making unnecessary claims on the professional's time: "everybody's got it". The accusation of medical malpractice was also frequently made; they often expressed the sentiment that "there's no point in seeing the doctors because they never do anything" and that symptoms were not treated from the root cause: "all the doctors ever do is give you painkillers". They felt that consultations were overly perfunctory and that symptoms were not thoroughly investigated. Mumtaz complained pointedly that: "when I go somewhere I'm so patient they forget I'm sitting there". There was thus a widespread mistrust of health professionals and complaint about their callousness and lack of interest in their patients.

She [GP] go to me, oh so what you've got back aches? I have them too. She said so what you had panic attacks, everybody have it. You know she took my file and she bang on the floor.

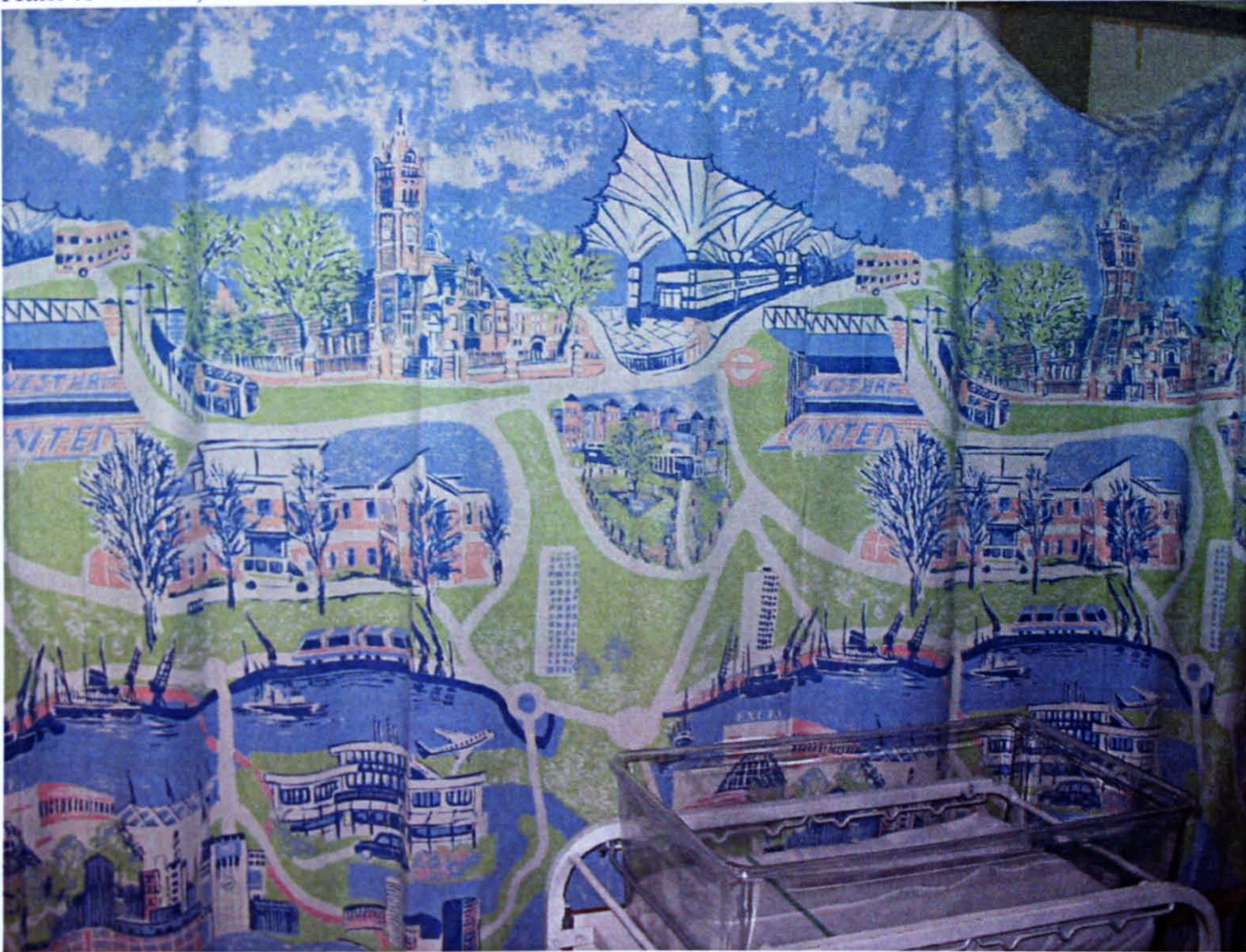
Mehk [female, 35-39 years, long-term condition]

The Valdas complained of distinctively bad experiences of diagnosis at the hands of their GPs. According to their accounts, health professionals simply assumed that *takleef* (suffering) was a natural part of the ageing process for women, rather than a sign of pathology. As Nasreen recounted: "my GP says that if you're over forty you just have to accept being ill". The Valdas blamed the delays in diagnosis, the protracted uncertainty around the nature of the disease, and the lack of treatment on the obdurate failure of GPs to interrogate their symptoms. Some of the Valdas, however, resisted the idea that their health problems were natural, and felt quite strongly that their health conditions were pathological and required medical attention. Suraiya expressed a common sentiment:

According to them we're just old, so we're bound to have problems. For instance, I've got a pain there [indicates to knees] but my GP doesn't take any notice. He just takes his burden off his own head, and refers me to go to some other place or some other hospital. Even if the person is dying they refer you on.

Suraiya [female, 55-59 years, long-term condition, translated from Mirpuri]

Plate 8: Cubicle curtains in Newham General Hospital, 2007. The curtains depict Stratford station, East Ham town hall, the Excel centre, West Ham United stadium and the Tate and Lyle factory.



Source: author's own.

The pervasive talk about malpractice and being made to feel illegitimate express a ‘politics and poetics of complaint’ (Wilce 1998a) about the imbalance of power and the marginalisation of the informants in the face of health professionals. Most of the informants were dependent on the state for their healthcare, but they did not feel that they were treated well – or equitably – within it. Although complaints about symptoms not being taken seriously by health professionals are certainly not limited to Pakistanis (see Higginbottom 2006; Salway, Platt et al. 2007), it was common for the Pakistani informants to perceive and express their marginalisation in racialised ways. Despite its ethnically diverse staff, the public face of the NHS was identified with the state and White society. Several informants attributed experiences of malpractice to their status as a visible ethnic minority and suspected doctors of being lackadaisical because “they think they can get away with it”. Ismail, for example, felt that the popular perception of Pakistani men as violent and out of control was the reason why his father was rounded up by police cars and “locked up”, and treated “caveman-style” with medication rather than given talking therapies which might get to the root of the problem. Sugra complained that Asian people were treated in Newham General only after White people. Whether their complaints are ‘true’ or not is in some sense irrelevant; they illustrate how poor experiences of healthcare were interpreted in terms of racial exclusion.

Asaan lokan (our people) don't get any help. Apne lokan ni help karne lekin asaan lokan ni help nay karne (they help their own people but not us). I'll give you another example. When you go to the hospital they call their own people in first and they just leave you sitting there. For five six hours they make me wait. They lose the files and they say the files have got lost.

Sugra [female, 55-59 years, long-term condition, translated from Mirpuri]

As other studies have also shown (Bowler 1993; Farooqi 1993; Gunaratnam 2001; Ali, Atkin et al. 2006; Atkin 2006), issues of ethnic identity pervaded the informants' consultations with health professionals. Particular problems arose over communication for first generation migrants who had difficulties with English. Assumptions about poor language capacities were not limited to migrants, however, and encompassed broader communication skills and articulacy. Hossein felt that "because I am an Asian, they think that I'm only supposed to speak up to a certain level... they don't think that anyone Asian can speak beyond that capacity. They're mistaken in that. With the next generation of Asians, their English is as good as anyone's". Yunus felt that his wife had been patronised and disrespected by the West Indian nurses because "they think you know, she doesn't know English". In relation to heart conditions, hypertension, diabetes and obesity, many of the informants were made to feel – and had in fact quite internalised the idea – that unhealthy Asian lifestyles were responsible for their ill-health. Yasin's physiotherapist, for example, told him that "you're Pakistani, I know your foods... you're going to have a heart attack by the time you're 40, look at the amount of junk you're eating! I go, which one's junk? He goes, your curries!".

Many of the health professionals in Newham were themselves Asian, which was appreciated by the first generation migrants as it allowed them to communicate in their "own language" and reduced their dependence on family members or health advocates for translation – in front of whom they felt ashamed and sometimes also mistrustful (see Edwards, Alexander et al. 2004). However, the fact that the health professionals were Asian did not necessarily mean that the informants were able to "feel easy" before them. Some of the informants actually preferred to see White professionals than Asians, who they saw as part of the same society (*maashra*) and associated with the threat of gossip or moral judgement. Umbreen, for example, preferred seeing White counsellors to Asian counsellors as "I'd feel as though they're judging me. I might see my sister in them, I might see my mum in them, you know?". It was quite common for the informants to express anger about the treatment they received from Asian doctors. They accused them of talking down to Asian patients, being arrogant, deliberately not using their "own language", not

referring patients on because they were too proud to admit that they knew less than a consultant, being rude, and playing the system for money. This resentment seemed to have arisen partly because the informants had more expectations about cultural similarity with Asian doctors and were therefore disappointed if this was not forthcoming. Nadeem, for example, complained that an Asian doctor had called his mother *tum* instead of *ap* (i.e. used the informal rather than the formal version of the pronoun 'you') and said that "Asian doctors have the worst attitudes towards the elders, they think that they are low and uneducated people. The English doctors are much better". The higher class status of the Asian doctors could therefore create as much social distance as the ethnic difference of the non-Asian doctors.

Disenchantment with the NHS had led at least four of the informants to purchase healthcare privately in the UK. In 1989, for example, Naseem and Rasheed paid £12,000 for Rasheed's angioplasty to be performed privately. The operation was funded by taking a second mortgage on their house. For six months following his operation Rasheed was in a deep depression, angry and betrayed by the British *nizam* (system) which had failed him despite the fact that he had worked and "paid his taxes" in the UK for nearly 20 years. Three of the other informants had gone to Pakistan specifically to purchase allopathic healthcare. Transnationalism presented a resource that allowed families to bypass all the hurdles to accessing treatment through the NHS, jump to the front of the queue and purchase high quality allopathic healthcare privately in Pakistan, where it was cheaper than the UK. Thus, although NHS healthcare had the potential to buffer the economic costs of long-term ill-health, the marginalisation of the informants in relation to state healthcare led some of them to take the cost of reproducing their family members onto themselves, and thereby subsidise the state – even though they were not really in a financial position to be able to do so.

5.3.2. Divergence from biomedicine and medical pluralism

In other cases, the informants' difficulties in securing a diagnosis seemed to reflect differences between biomedical knowledge and subjective lay experiences and presentations of ill-health, and the power of biomedicine over other systems of medical knowledge. The diagnosis of depression was particularly controversial. Many of the informants questioned the status of depression as a disease within Islam and Pakistani culture, echoing important questions from the literature surrounding the cross-cultural validity of depression and other categories of mental illness deriving from Western psychiatry (see Marsella and White 1982; Kleinman and Good 1985; Jadhav 2000). Some felt that depression was the consequence of a person's *duniyadari*

(materialism) and failure in religious steadfastness. In this sense, *mayoosi* (despair) and *nashukree* (ingratitude) were both sinful. Naila rejected her diagnosis of depression until she read in an Islamic book that it *was* a disease, which confirmed its reality for her. Four of the informants who were diagnosed with depression believed that it did not happen in Pakistan; either the social environment (*mahaul*) there was more supportive, or people there were too busy working in the fields to “think deeply about problems and get stuck in a cycle of thought”. Some of the Lads and Idher ki, particularly those who thought that Pakistan was in some way “backward”, felt that Pakistani people didn’t have “a good understanding of mental health”; “it would be classed as a very quiet subject”. Jamal felt that among Pakistani people “symptoms of depression are often dismissed as laziness or stropiness”, picking up a theme from cross-cultural psychiatry that in racialised societies the majority cultural expressions of mental illness are regarded as definitive (Fernando 1988).

The informants also tended to materialise emotional and mental distress through physical symptoms, such as pain all over the body, fainting, vomiting and disordered eating or sleeping, and sensations relating to the heart – sinking, being heavy, low, too big, tight, in agony, suffocating or experiencing palpitations (see Good 1977; Good and Good 1982; Krause 1989; Fenton and Sadiq-Sangster 1996). Women complained of protracted menstruation and unusual blood flow, and of their hair thinning and falling out and of their faces losing their shine due to worry – a sign of the loss of their youthful feminine beauty. When doctors were unable to determine the nature of a disorder through an identifiable biological explanation the condition became ‘medically invisible’ (Ware 1992), the objective reality of the symptoms the individual was experiencing was questioned, and a diagnosis of ‘psychosomatic’ illness was given. This was understood to mean “it’s all in the mind”.

A diagnosis of psychosomatic illness was often felt to be unsatisfactory. It effectively amounted to a non-diagnosis, casting doubt on the reality of the symptoms and failing to resolve the nature of what they actually meant, and undermined the legitimacy of the individual’s claim to being genuinely ill. Interestingly, there seemed to be awareness among health professionals locally that presentations of unidentifiable bodily pains among Pakistani patients might be indicative of mental illness. For example, Naila told her GP that she was having pain all over her body, and was prescribed anti-depressants. Equally however, the assumption that illness might be psychosomatic sometimes delayed the diagnosis of an underlying physical disease. Amina’s physician initially diagnosed her symptoms of heart disease as mental illness and said that “you have to see a psychologist because you are thinking too much”. Mumtaz was triumphant when

her gall stones were at last diagnosed, as her GP had told her that “you only believe that you are unwell”.

Some of the informants had still not been diagnosed with a specific, definable health condition by the time of fieldwork. For those whose symptoms persistently evaded a medical diagnosis, the verdict of psychosomatic illness was frustrating and unsettling. They spoke of being made to feel like a hypochondriac or “problem child” – or worse, accused of inventing their symptoms and being somehow mentally unstable. The undiagnosed informants were in a perennially insecure, directionless liminal area, neither well nor sick: indeterminately stuck between the states of ‘non-normal’ and ‘yes-positively diseased’ (Tishelman and Sachs 1998).

She [mother] thinks that he [the GP] doesn't give her enough attention and doesn't really look at what she's got and doesn't sometimes give her the right medication because I think once it's happened where he's given her like medication which she shouldn't have given her and that's caused things. She gets really upset, she hates going to the doctor but she has to. And she knows it that the doctor just thinks that she's come... It's like, have you come here again? It's just a nightmare because they don't know what's wrong with her, she gets depressed, everything goes in a circle around and around.

Ayesha [female, 20-24 years, family member]

The failure to secure a meaningful biomedical diagnosis or effective treatment was an important factor that encouraged the informants to turn to alternative healthcare providers including homeopathy and *hikmet* (Islamic medicine). For people with mental illness or whose physical conditions were inexplicable or unidentifiable according to biomedicine, consultations with *imams* (clerics), *peers* (saints) or *hakeems* (practitioners of Islamic medicine) could allow diverse symptoms to be apprehended as of spiritual or supernatural origin, which presented alternative, sometimes more satisfactory explanations of the health condition and more effective ways of treating it. However, there was wide variation in the extent to which the informants gave credence to such explanations, along the lines of gender, age, and educational status; contestation as to their place in orthodox Islam (see Dein 2005); and an unwillingness to reveal such medical pluralism to biomedical health professionals. This reflects the power of biomedicine over other systems of medical knowledge, as well as the informants' own ambivalence towards understandings about health which they felt that other people judged as “different” and “backward”. This is illustrated by Farhana's account of her aunt's possession by a *bahr ni cheez* (“thing from outside”) or *djinn*:

In her [aunt's] situation it's different because it's like a spirit problem. Whereas psychiatric problems, that's like a totally different issue, you're going through depression or you're mentally disturbed, you're lacking something in that sort. With her situation it's just a spiritual thing on her side. So you know it's quite hard to explain to someone who's White cos first of all they don't believe in them [djinn] and it doesn't happen to them [Whites], and you can't blame them [doctors] for not believing her because it doesn't happen to them. In our Asian community it happens a lot, but they [doctors] wouldn't understand what she's saying.

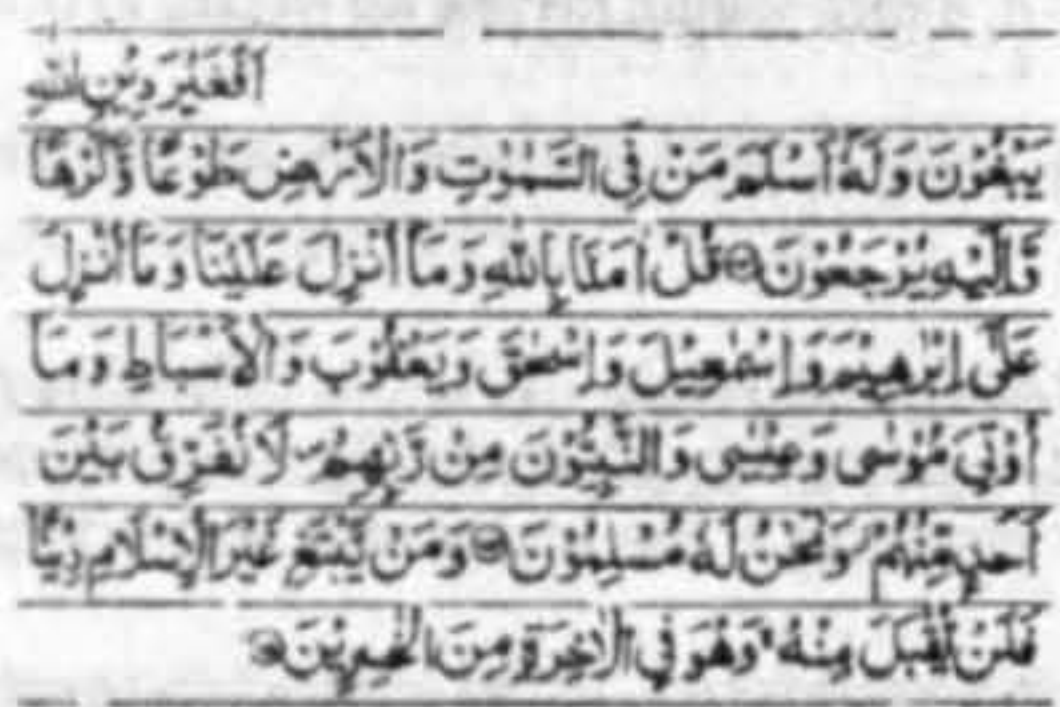
Farhana [female, 30-34 years, family member]

Plate 9: Extract from book of remedies from the Holy Quran. Quranic verses may be recited to request God's mercy and relief for a variety of misfortunes and ailments including long-term health conditions.

Who have believed and whose hearts are at ease in the remembrance of Allah. Verily in the remembrance of Allah do hearts find rest. (13:10)

Same to be done as in A.

PALPITATION OF THE HEART



(Refer to Qur'aan (3:17) for translation:)

The above verses are said to be most effective for palpitation. They should be written on the inside wall of a new clay utensil. Non-poisonous ink should be used. Saffron is best. The plate should then be washed with a cup or two of rainwater or water obtained from such a well whose water is not exposed to sunshine. (A tube well or bore hole is one's best bet). The patient should be made to drink this water. Insha-Allah, relief will be found.

AILMENT OF THE HEART

A. Recite Surah Inshiraah (30th Juz) and blow on the patient.

B. *وَكُلَّمَا سَأَلْتَهُنَّ خَطِيئَتَهُنَّ لَئِن لَّمْ يَكُن لَّهُنَّ بَطْشٌ مِنْ رَبِّكَ لَأَنكِرْنَ*

And we remove whatever rancour there may be in their hearts.

Write the above verse on a new clay utensil using either saffron or rose water. Wash it and drink the water.

Insha-Allah, the pain will go away.

STRENGTHENING THE HEART

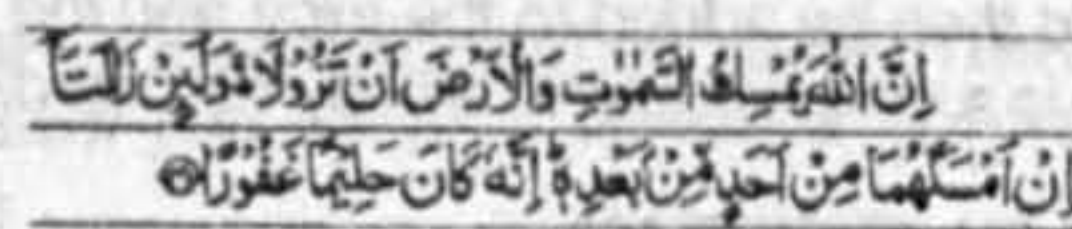
If the Beautiful Name of Allah *الْمُبْدِي* (The Excellent) is recited a number of times and *blown* on a morsel before eating it, the heart will be strengthened — Insha-Allah.

TO ACQUIRE FREEDOM FROM MATERIALISM

الْوَاحِدُ الْأَحَدُ (The One And Only)

To acquire independence in the heart recite the above Name of Allah 1000 times. The importance of material objects will depart from the reader's heart.

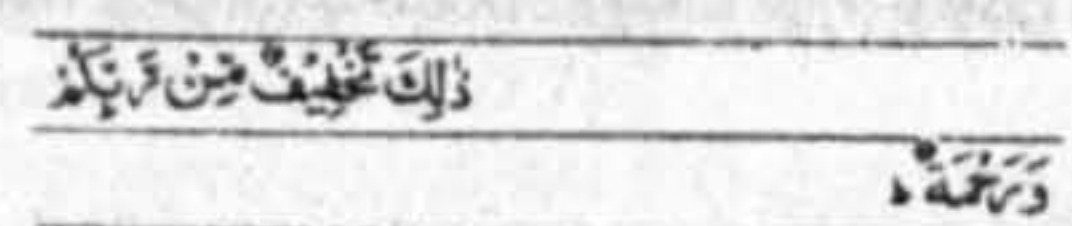
DISEASE OF THE SPLEEN



Lo! Allah grasps the heaven and the earth that they deviate not. And if they were to deviate there is not one that could grasp it after that. Lo! He is For-Ever Clement, Forgiving. (22:17)

Write the above *ayah* on paper and tie it on the portion where the spleen is situated. Insha-Allah the disease will be cured. (A plaster can be used to fix the *taweez*)

FOR THE DISPLACEMENT OF THE NAVEL MUSCLE



Source: Thanavi (2001), p.61-2.

Despite the ambivalence towards alternative forms of healthcare, many of the informants procured services from *peers* and *hakeems* out of a compelling fascination with *djinn* (spirits). The informants felt that increasing economic differentiation and the ensuing backbiting, rivalry and jealousy had contributed to an increase in *nazar* (the evil eye), *baddua* (curses) and *jadhoo* (black magic) among Pakistanis locally. A book Haseena had borrowed from a library in Bradford on *rukhani ilaaj* (spiritual treatment) was eagerly passed around networks in East London: "it was only one book that just go round and round". At the heart of medical pluralism

was pragmatism: a willingness to use any means, in pursuit of a cure. Haseena had reservations that the use of Islamic healers represented a form of *shirk* (polytheism). Nonetheless, she followed her friends' advice, and eventually took her husband Razzaq to see a *peer* in Birmingham.

Plate 10: Data Sahab shrine, Lahore, 2004. Data Sahab is the patron saint of Lahore and his shrine is one of the most popular destinations where *barelwi* muslims make appeals for relief from misfortune including recovery to good health and forgiveness for the sins of those who have died.



Source: author's own.

The choice of alternative treatments imposed economic costs. Frequent complaints were voiced surrounding the proliferation of 'fraudy' *peers* (saints), who were said to be cynically making money out of guileless, vulnerable individuals. The transnational nature of Islam meant that certain healing practices required travel; the informants undertook pilgrimages to Saudi Arabia (*zam zam pani* or holy water from Mecca Sharif was also supposed to be imbued with healing properties) and to the shrines of *peers* in Pakistan and elsewhere. Zubia, for example, had run into several thousand pounds of debt as a result of procuring the services of *hakeems* (Islamic healers) in London.

My brother had somebody working with him in the factory, and they were Muslim Africans. So he goes well you know, let me go and see your sister... These people doing the Quranic verses, they

used to go into jungles and things like that. And hikmet (Islamic medicine). So many people did help me but they want money. I've given so much money just to get cured. You know, you try several doctors, you try homeopathic, you try this – whoever tells you to try somebody, you just go and try it but you don't try without money. You have to pay so many thousands of rupees! Those people from Africa were charging me 50 pound every time... And everywhere my dad or my brother took me, they just got fed up because of paying the money.

Zubia [female, 40-44 years, long-term condition]

5.4. Negotiating sickness in the home

The household context was an extremely important influence on the negotiation of long-term ill-health, and over and above other interpersonal arenas, the domestic group had a special place in the informants' accounts. The distinction between the reactions of people they lived with and “outside people” was stressed. “If you live with it you have the experience, you're more sympathetic”; “we live with her, so we *know*”. Yasin echoed the same sentiment:

She [wife] knew something about the pain I was suffering, she knew it, but sometimes I'd just blow a fuse, I'd just go off the rail totally. Yeah, she knew, she stayed quiet, she wouldn't fight back at me or, verbal attack. She'd be cool about it. The rest of my family didn't. They expected me to be the same. Oh, why don't you come play football, why don't you come walking, why don't you come to the park. I was just, what's happening, what the fuck's wrong with you, are you lot blind or something?

Yasin [male, 30-34 years, long-term condition]

However, the domestic group was not merely a location or the set of kin most directly affected by long-term ill-health: in practical terms, the family was also *constitutive* of the ill-health. As Gregory points out, the family represents the everyday setting of routines, activities and interactions through which the meanings of long-term ill-health emerge and are reconstituted on a daily basis (Gregory 2005). The ways in which they presented their ill-health, and the ways in which household members responded were central to how ill-health became socially meaningful. The contingency of the sick role on the specific responses of other household members is illustrated by Asif's younger brother Idrees. Idrees had the same hereditary visual impairment as all Asif's siblings, although according to Asif, Idrees's was the least profound. On top of that, Idrees had some kind of mental illness that meant that he sometimes had “sticky patches” when he would “flip” and lash out violently at others. The psychiatrists had not apparently put a finger

on exactly what it was but Asif's family called it "learning difficulties". Asif was frustrated by what he saw as Idrees' tendency to "play on" his learning difficulties and wallow in his disability to the extent that he would not even get up and make himself a cup of tea. He blamed Idrees' behaviour on the reactions of other family members, who allowed him to get away with what Asif considered to be inappropriate use of the sick role. In particular, he was critical of Idrees' wife Asiyeh, who would "never refuse him anything". I would suggest that Asiyeh's response ought to be understood in relation to patriarchal ideologies about widely roles as well as her recent arrival from Pakistan, which was associated with a weak gendered position in the household; I discuss this more in Chapter 8. Asif was more approving of how his younger brother Nasir handled Idrees, which was more bullying and therefore less encouraging of malingering.

He's intelligent is my brother, he's articulate but he... plays on other people's sympathies, I think that's the best way of putting it. So for example he will say please can you give me a glass of water instead of getting up and getting it himself. He will say can you give me a spoon and he might be sitting right in front of them but you know because he wants to draw attention to the fact that he can't see very well and he's got the learning difficulties you know he says "give me a spoon please". So you know, give him the spoon. And Nasir doesn't tolerate that in any way whatsoever. He says "Idrees, where are the spoons?". And he points to them. And he says "well, grab one then". Like that. So you know there's different tolerance levels I suppose, to what he can and cannot do in the family.

Asif [male, 30-34 years, family member with own long-term condition]

The service providers I interviewed expressed concern about the influence of "Asian families" on people with long-term ill-health. They believed that Pakistani families were more permitting of a person taking on of a permanent sick role because they "pampered" the sick person, obviating the need for people to "fend for themselves". Their comments echoed various claims in the literature that the ethos of *ikathe* (togetherness) and interdependence in Asian families makes long-term sick people more likely to become 'dependent' (i.e. more immersed in the sick role) than their White British counterparts. Independence is one of the major areas of identity that is affected by disability in Western society and one of the central normative values around which 'preferred' identities are reconstructed (Gavlin 2005). Ahmad has contrasted this with the South Asian experience: "some of the arguments about loss of control or independence in relation to the social model of disability may seem over-Westernised to many for whom interdependence, mutual support and reciprocity are the hallmarks of social and family relationships" (Ahmad 2000) (p.2). Similarly, Hussain and colleagues argue that young Asian disabled people balance the need to

exercise control over their lives with a sense of mutuality, interdependence and reciprocity. Developing a separate identity from their parents and exercising control, for example, is not always equated with leaving home as it often is for their White counterparts (Hussain, Atkin et al. 2002).

Another argument is that the fluid and ready substitution of the activities of the long-term ill person by other family members in an integrated family system means that they are less challenged to persevere with (or [re]learn) how to carry out these activities themselves. Gardner, for example, relates the frustrations of physiotherapists working with elder Bengali men who complained that “they do not want to be active or independent... after a stroke or illness they become completely dependent on their carers (usually their wives) and on the services and facilities provided by the state” (Gardner 2002) (p.166). The argument therefore runs that the individualism and independence characteristic of Western society is less marked among South Asians, drawing from the common idea in anthropology that South Asian concepts of personhood are relational and embedded in the social group rather than in the individual (Dumont 1967); and that there are therefore fewer barriers to the sick role.

The accounts here, however, suggest that it was not so difficult to translate the Western concept of independence for the informants. Rather, it was the specific *implications* of taking on a dependent sick role that were problematic. It was not the ethos of *ikathe* (togetherness) *per se* which shaped a person’s propensity to take on the sick role, but the position of the individual in relation to others. Individuals who had more power in the household system, such as elders and men in general, inhabited a sick role with greater ease. Younger men and middle-generation women tended to be more attached to their everyday activities and attempted to push themselves harder to remain “in control”, reflecting their own ambitions and concerns with how long-term ill-health would affect the balance of power in their intra-household relationships. Indeed, in many cases it seemed that the informants did not desire independence *per se* so much as the feeling of being indispensable to their households; they wanted to feel valued, and not a “burden” on others. To borrow a concept from the literature on emic articulations of gendered power South Asian context, the informants sought to be *central within* their households rather than independent *per se*; they sought to consolidate strong affective ties with other family members, through which they could garner other resources (see White 1992; Unnithan-Kumar 2001; Mumtaz 2002). The concern with independence ignores the fact that many of the informants’ interests were vested strongly in maintaining gendered family roles, and that “household

members, both men and women, are tied together by strong emotional and structural bonds” (Salway and Mumtaz 2006) (p.20).

5.4.1. Generation

The propensity to take on a sick role was strongly affected by age, although importantly, this was bound up in inter-generational concerns rather than chronological age. Long-term ill-health for the Babas and the Valdas involved noticeably less ‘biographical disruption’ (Bury 1982) than for the young. Research tends to find that although ethnic minority people become frailer at a younger age than their White counterparts they feel more positive about ageing. Instead of connoting decrepitude and a loss of abilities, for Black and Asian elders the process of ageing means acquiring an enhanced status in the family and community (Moriarty and Butt 2004; Bridge, Cylwik et al. 2006). This positive estimation of ageing was strongly espoused by the informants, and values around “respecting” ones elders were subject to powerful normative pressures (see also Harper and Levin 2005; Murtuja 2005).

Ideologies of filial support and intergenerational reciprocity gave the Babas and Valdas powerful claims to attention from other family members. Intergenerational relations were also intertwined with the collective narrative of what Werbner has called the ‘community of suffering’ (Werbner 1980), which provided additional moral authority for being ill and taking on a dependent sick role. The onset of long-term ill-health was explained as the inevitable result of years of physical labour done in arduous circumstances and living in cramped, overcrowded, inadequate housing in the struggle to make a livelihood and get established in the early years after migrating to the UK. The suffering they experienced was thus seen as the legitimate product of the earlier sacrifices they had made on behalf of their children and *biraderi* “back home”. The guilty sense of obligation that knowledge of the elders’ prior sacrifice produced in the young was captured pithily by Ricky in one of his poems: “my parents were hard-working and scared; I am comfortable and lazy”.

The people who came here first they had such strong determination to work, not just for themselves and their families but you’ve got to remember they were supporting five or six families back home... A lot of the health problems our elders have, it’s cos at that time they were working so hard and they were living in quite poor conditions as well.

Asim [male, 25-29 years, family member]

The Babas' and Valdas' positive orientation to ageing was, however, contingent on their enhanced status and claims to support being appreciated by other household members. This was illustrated by Bashir and Sadiq's accounts, which squarely defined wellbeing in terms of harmonious intergenerational relations. They presented themselves as successfully ageing people, well adjusted to their health conditions. The basis for their success was that they had managed to bring up their children well, educate them well, marry them well and get them "set"; and that the children and other family members showed their love by looking after them in various ways, asking regularly after their state of health (*haal chal puchna*) and providing them with *khidmat* (care). Provided that the children turned out well (*bachhe achhe nikaley*) and that the family were loving and supportive, the Babas and Valdas were able to adjust well to their health conditions and inhabited a dependent sick role relatively serenely. As Bashir reflected, "what kind of life I have there? That's a comfortable happy life".

However, in espousing the normative values around filial obligation and the authority of elders, the informants were not merely adhering to a reconstructed Pakistani culture, but reproducing or challenging these ideologies on their own terms. The Babas and Valdas had 'dependency anxieties' (Vatuk 1990), but these were not concerned with relying on family members, but with what would happen if their family members were *not* there for them. The vicissitudes of wilful children were usually their most pressing concern. Despite the presence of state welfare, fears about future insecurity were sometimes frighteningly palpable, especially among those who were already living on low-income or facing the prospect of an old age with just a state pension. The moral *mahaul* (environment) in the UK was felt to have a corrosive effect on children's filial support, as I elaborate in Chapters 6 and 7. Many of the long-term sick informants with *jawaan* (grown-up) children expressed the desire to die active, which revealed a sense of insecurity about how they would be treated by their children if they were to become so incapacitated as to be unable to work. The 'dependency anxieties' of the ageing informants expressed the extent to which their interests were vested in informal claims from their children and their insecurity in the absence of viable alternatives.

They can be very, very nice kids at times but they can be very, very horrible as well. And then I get all worried what's going to happen to me, who's going to look after me if I'm old.

Sayeeda [female, 35-39 years, family member with own long-term condition]

Younger people were less inclined to take on a sick role, and showed more 'biographical disruption' and inner conflict surrounding the issue of dependence. Interestingly, however, some

of the younger informants seemed to have responded to long-term ill-health by prematurely taking on the entire social identity of the *barhe* (elders). It infiltrated their physical presentation, dress, ways of walking, ways of thinking about the world and how they related to others. Struck by long-term ill-health in their 30s, Ubaid and Yasin had developed mentalities characteristic of the Babas. Their demeanours were cultivatedly religious and wise. They had begun to wear *daris* (beards) and *shahwar kameez* instead of “English” clothes. Their Muslim identities had strengthened in response to many different factors, but the ill-health had played its own role. They related to other people like the Babas. They no longer related strongly to their peers and felt that they had outgrown them.

I think as I'm getting older and maybe it's the illness as well, it's all like putting me in my place, making me more humble. People see me and they think, changed. What happened to you?

Surprise, there's an element of surprise among some... Maybe I'm getting older, I've got different thoughts and ideas you know, maybe they're not matching up, you know, like people think the same and they'll be more sort of like synchronised with each other. When you're not on that level any more or they're not on the level then slowly all of that declines, doesn't it?

Ubaid [male, 35-39 years, long-term condition]

5.4.2. Gender

Gender shaped the informants' propensity to take on a sick role as well as the construction of the sick role. Broadly, medical sociology has cast the sick role as more problematic for men. Parsons proposed that as a result of traditional gender roles men were more resolutely stoical than women before the sick role is sanctioned, but that once ill, they showed exaggerated weakness, the display of dependency being less open and structured in the case of women (Parsons 1951). Bury and Charmaz have argued that women cope better with long-term ill-health because acceptance and passivity align more with traditional female roles, whereas the unpredictability and uncertainty entailed by long-term ill-health pose a threat to traditional masculinities with their emphasis on control and taking charge (Bury 1988; Bury 1991; Charmaz 1994). However, the specific constructions of gender among the Pakistani informants in East London fracture some of these stereotypes. Men and women *both* expressed stoicism towards long-term ill-health, but the motivations and meanings attached to it differed in accordance with masculine and feminine ideals. Furthermore, gendered constructions of the sick role were relational and dependent on the individual's position in relation to other men or other women; they were therefore structured by cross-cutting hierarchies of power such as generation, household position and class. Individuals

also challenged the normative gendered constructions of the sick role on their own terms, within the limits set by the 'conditions of possibility', according to the stakes that were at hand.

5.4.2.1. Women

In comparison with the men, the women generally described more awareness about their health before the onset of long-term health conditions; in most cases they had already come into close contact with medicine through their experiences of reproduction and childbearing. Indeed, many women identified complications during pregnancy and childbirth as the origins of their present health conditions. The informants had a strong normative discourse of female stoicism based around women sacrificing their health in the struggle to bring up children and reproduce the family. Ill-health was cast as a legitimate response to 'role overload'; a lifetime of overwork and being overextended and overcommitted, putting others needs before ones' own, keeping the peace, being unable to say no, and possibly also juggling caring roles with employment. Ill-health was thus constructed as the legitimate product of over-engagement with a way of life sanctioned by normative values (see also Kleinman and Ware 1992). The informants also saw such gendered sources of stress in relation to collective identities as Pakistani women. Ayesha believed that her mother's ill-health could be attributed to the poor lot of "Asian women": "she doesn't know why it's been brought on, she thinks its pressure, which it could be; you know how like Asian women they are under this constant pressure".

All the pressure is on me... You know everybody else makes a fuss, but me I quietly do it. Because I think, somebody's got to do it. And I start feeling guilty that, oh no, if I don't do it this will happen that will happen. So all these sort-of pressures. Twenty years back, when I was young, you could keep up with you know, all these sort-of anxieties, stress, whatever. As you get older your body gets weaker and that's why I think I've developed these things over the years... But I want to do it, that's the thing, I want to do things for my family.

Shaheen [female, 45-49 years, long-term condition]

In general, there was a greater disjunction between subjective ill-health and the public performance and recognition of long-term ill-health among the women than the men. As I mentioned in Chapter 4, many of the female informants cried during the interview, describing themselves as "suffering in silence" and saying that they had never openly talked about their ill-health before. The interviews elicited powerful emotional performances (see Grima 1992; 2002).

Despite their ill-health, they tried to keep up a brave face and get on with the everyday work of living to protect family members from knowing about how much they were suffering.

This normative gendered sick role was summed up by the notion of having *sabar*. *Sabar* is a multi-layered term, often translated as patience or tolerance, but it also has connotations of endurance, perseverance and steadfastness. *Sabar* was associated with religious merit (*sawab*). Misfortune, such as ill-health, was understood to be a test (*imtehan* or *asmaish*) and a call to turn towards God. Suffering was said to be one of God's ways of making people remember Him more often and many of the informants therefore felt that people who were long-term sick were closest to God. Although *sabar* was supposed to be desirable in any Muslim, the indisputably feminine nature of the quality is illustrated by the observation that for men '*sabar*' was a pejorative nickname used to denote somebody who was subordinate, walked over, taken advantage of, weak and effeminate. Studies of gender systems in North India show that *sabar* is a key part of the construction of self-subordination within the patriarchal notion of the 'good woman': "a silent shadow... veiled and mute, accepting her subordination to her in-laws, submissive, chaste... passive and unquestioningly obedient" (Raheja and Gold 1994) (p.3-4). It is important to note, however, that many of the women did not see themselves as victims of patriarchy so much as heroically sustaining the viability of their families.

This is the secret stuff of us ladies. Sabar (steadfastness), yaqeen (faith), takleef (hardship). It's all a test, life is a test. You need to trust in your faith, in your life experiences. Why are you here? First you need to discover that. Allah has given me so much takleef (hardship) in my life. The point is that you have to get through it. Bardasht karna parta hai (you have to bear it).

Nusrat [female, 45-49 years, long-term condition, translated from Urdu]

Moreover, it was not equally important for all women to have *sabar*. It was particularly important for women in the middle generation, who had responsibilities of *khidmat* (care) for parents or in-laws as well as for their own children. The normative ideals of sacrifice involved in being a daughter-in-law were especially strong: "if the daughter-in-law can bear it, then the whole house stays happy, because if she can bear it she can keep her husband happy, her father-in-law and her mother-in-law. If she doesn't, then five people will suffer".

There was also contestation among the female informants around the normative ideals of *sabar*, silent suffering and sacrifice. Divergent opinions were articulated by the Idher ki in particular, many of whom saw the sacrifice that their mothers had made for the good of their families as a

heartbreaking expression of their mothers' powerlessness in the face of their husbands and senior kin. Ayesha described her aunt as "one of those naïve women who accept what happens to them and doesn't complain about it" and said that it was "a tragedy". The female informants often said that "children today" or "children in this country" did what they wanted (*apni marzi karti hain*) – which they saw, in this context, as a positive change. Sugra said that "nowadays children say what is on their minds regardless of how it may affect anyone... they have a lot of self-respect"; Mariam commented that "over here nobody takes crap from everybody, everybody does their own stuff". Several of the women told their own daughters to be more assertive in claiming attention from others. Nasreen said that "I tell my daughter, don't follow in my footsteps – keep your health, and stay happy". Shaheen's mother also challenged the values around *sabar*: "my mum said to me that you don't look after yourself, you look after people but you don't look after yourself". The women thus employed their own agency to resist normative pressure to do *sabar*. Even if they themselves could not resist the ideal of *sabar* as a route to gaining honour and centrality, they were not necessarily committed to retaining and reproducing these normative ideals in future generations.

Furthermore, as Wilce points out, concealing suffering and taking it onto oneself could itself be an expression of agency, albeit one which involves colluding in the hegemonic structures that offer women the possibility of achieving higher status at the end of a long road to submission (Wilce 1998b). Uncomplaining endurance offered rewards to women through allowing them to claim moral high ground. It is important to appreciate the leverage that women could gain over others through their reputation for *sabar*. Ironically, the value of silent suffering really came when it would be tacitly acknowledged by others and praised. For instance, when I asked Haseena how it made her feel when someone told her that she had *sabar*, she replied: "it feels very helpful. It feels very helpful that, *vaqai mein main ne sabar kiya itna* (I have really done that much *sabar*). That someone can see that. Because most of the time in the house where I am, I don't feel that anyone sees that I been through a lot. If someone says that then it's just... I do think that if someone can see that I been through something". The knowledge of how much *sabar* a woman had done evoked a guilty sense of obligation that could motivate family members, particularly children, to behave in accordance with women's own desires. Some of the women therefore used their health conditions to sanction increased control over tension-ridden relationships within the household and effect transformations in their lives. Indeed, some women had evolved subtle and masterful ways of signalling their suffering to others. Long-term ill-health entailed a complex performance, akin to what Herzfeld calls a 'poetics' of selfhood; a kind of

dramatic projection of elements of an individual's self-identity into the politics of social interaction (Herzfeld 1985).

She's a fantastic woman, an Asian woman because she makes lots of sacrifices and she's very tolerant. But she's tolerant in a hidden sort of way where she doesn't tell people that she's tolerant and then she kind of uses it against us she says that we're not good children.

Ayesha [female, 20-24 years, family member]

Thank god the children are grown up now. So they do not need much care. They look after me when needed. If I do not tell them when I am feeling ill they can make out seeing my face. They then tell me to sit down and relax. Children look after me as they know that I am their mother. But now they realize what I did for them. I never let them feel that I was unhappy.

Nasreen [female, 45-49 years, long-term condition, translated from Urdu]

In the hands of women with few alternative sources of power, therefore, long-term ill-health could be a powerful lever over other family members. These 'poetic' or pragmatic uses of the rights and obligations entailed by the sick role were an important part of the battery of strong matriarchs and a route to becoming more central within the household. However, like other 'weapons of the weak' (Scott 1985) such actions thwarted but did not reverse the status quo of power relations; and they were heavily dependent on others' emotional reactions. If existing relationships were weak or hostile and family members did not care about the long-term ill woman, there was little leverage to be gleaned from *sabar*. The success of pragmatic uses of ill-health therefore depended on the existing centrality of the woman to the household; the extent to which she was embedded in a network of loyal and positive relationships with kin.

When I've been really fighting with my husband and things like that, a few times it has happened when I get too much distressed and I end up having an asthma attack... I have mentioned it to him but he doesn't take it seriously. He thinks I'm just saying it. But I don't expect him to care, you know? To um not really... stop fighting I suppose.

Nafisa [female, 35-39 years, long-term condition]

5.4.2.2. Men

Arber and Thomas' generalisation that "women are not easily seen as healthy and men are not easily seen as ill" (Arber and Thomas 2001) (p.98) resonates in many ways with the accounts

given by the male informants. The men's accounts had a pervasive resistance to seeing symptoms as indicative of underlying ill-health. Most of the men said that before the onset of ill-health they were *hatta katta* or *tandroost* (healthy), "fine", "fit", "strong", or "could do whatever they wanted"; their bodies were largely invisible, ticking away constitutively in the backgrounds of their lives rather than experienced consciously. Provided they could fulfil the functions needed to carry out their everyday roles of family, community and workplace, many of the men paid little attention to their health: "I do enough exercise to work the amount of work I do". For some, the memories of their youthful bodies stopped them from being very proactive about interrogating the symptoms of ill-health when they first arose: "I'm young, I'll work this out, this'll be gone in a year's time". Delays in treatment-seeking were common as well as relying on their own 'lay expertise' rather than the knowledge of professionals. Maintaining the family health was regarded as part of women's everyday responsibilities, and it was often a wife or daughter who encouraged the men to seek diagnosis and treatment.

Like the women, the men talked about the importance of bearing their symptoms without sharing the pain, and continuing to perform their everyday duties. However, there was much less emphasis on suffering in silence, except for those who seemed to embody marginal or subordinate masculinities. Bullied by his uncles, Naem locked himself in his bedroom, refused food and sleep, wrote things on the walls, self-harmed and rued that "no-one knew that time that I was suffering". Rather than *sabar*, masculine stoicism was associated with qualities such as strength and overcoming hurdles despite challenges. A common sentiment expressed by the younger men was that they "ignored it" and "tried not to think about" being long-term ill. As Faisal put it: "I enjoy my life. And I don't do things like oh, I'm sick. I'm not sick. Fully fit". They were averse to being pitied. Yasin scoffed that: "I do try my best to conceal it. I don't want people feeling sorry for *me!*". Liaqat, in keeping with masculine ideals concerning emotional distance, did not want to talk about his problems with other people: "I don't want any support. It's all the same to me".

The possibility of appearing weak in relation to other men seemed to influence men's propensity to take on a sick role. Yasin was unwilling to voice his concerns about his back pain in front of his "old man", who was a tall, square, strong individual with a loud voice and a powerful charisma. He used to give Yasin an affectionate thump on the back whenever he saw him; "how you doing son, *boof*, like that". When he was around his father Yasin began to feel as if worrying about his back ache was a form of weakness or malingering, so he kept quiet. Yasin continued to work and go to the gym and ended up doing irreparable damage to what turned out to be an

inflamed disk; in keeping with research suggesting that performances of hegemonic masculinity are often bad for men's health (Sabo and Gordon 1995; Cameron and Bernades 1998). However, masculine ideals need to be located in specific historical and social contexts. For many of the informants, it seemed that the ideals of the working-class industrial labourer, imbued with the connotations of strength, dignity and pride, were locally dominant. As Watson points out, over-generalisations about gendered responses to ill-health tend to miss much of the vibrancy, complexity, self-deprecating humour and morality of male experience (Watson 2000).

I thought "oh my god, something's gone wrong here". My father went "aah, there's nothing wrong with you". He was one of them old dockyard boys, you know what I mean, "nothing wrong with you, you're alright", yeah, "you lazy git", blah blah blah. I went "alright then".

Yasin [male, 30-34 years, long-term condition]

Despite the ideals of masculine stoicism, it was noticeable that when men did take on a sick role their families seemed to permit them to relinquish all their activities, and they were left much freer of responsibilities than the long-term ill women. The men's accounts contained far fewer complaints about their ill-health not being taken seriously by other family members. For example, after Ubaid was forced to leave his job he went to Pakistan for a few years, leaving his wife at home to make sure that the children's school work did not suffer.

I felt good for a little while. I thought I'm free of any kind of responsibility now I can do a bit of travelling... filling some desires, just going out and about.

Ubaid [male, 35-39 years, long-term condition]

As a trivial example, these gendered norms around the performance of the sick role underlaid Shamim's joke that a common cold in her husband would turn into "man flu". She was poking fun at him for hamming up his sickness, malingering and getting her to run around after him; but although she would joke about it with her female friends, she did not object to it, it being part of her wifely duties. Men's more elaborate performance of the sick role was, therefore, evidently related to the greater power they enjoyed in their households. However, the issue was not simply maleness or femaleness, but the extent to which the individuals had power over others: their 'centrality' in their households, which could be developed through their structural roles and affective bonds. Gendered constructions of the sick role were therefore relative to the individual's position in relation to other men or other women.

5.4.3. Household roles and responsibilities

The social consequences of long-term ill-health were considerably bound up in the wider context of household roles and routines. The accounts showed that access to the sick role depended considerably on how indispensable the individual's everyday roles were considered to others in the household, and how threatening it would be to various household members if their roles were to be relinquished. This was partly a matter of household composition. Where there was another sick family member who was already the primary focus of family concern and energy, particularly a senior adult or a child, it was difficult for the main caregiver to claim the attention required to openly adopt a sick role. As the female informants were often the primary caregivers in their homes, they had difficulties in receiving care from others. They placed a high premium on maintaining their roles as caregivers despite their ill-health, and in particular, on protecting their family members from the pain of knowing about their health condition. Many of the women claimed to keep their suffering to themselves so that their family members would not get worried: "my husband is like having another child, a big baby, you need to look after him like that. Men aren't strong, well they are physically yes but not emotionally"; "I didn't tell him how ill I am, I didn't tell him anything".

In his last days when he [father-in-law] used to stay very sick then a social worker visited us. She said that I looked more ill than him. She said that I needed more help than him. But in spite of all this I never thought of leaving him in the old home... This is my story. I never got any time to think whether I have any illness. I just took my medicine and did my work.

Nasreen [female, 45-49 years, long-term condition]

Informants who were in subordinate positions in their households would often not allow themselves to become too preoccupied with their ill-health; they said that they had to just "carry on" or "keep busy". Nafisa, who could not even summon the energy to de-louse her matted hair, wash her clothes or tidy her house, said "I'm probably suffering distress and things but I haven't gone to the GP. I don't get the time really". The idea that people who allowed themselves to rest would end up becoming more ill was frequently expressed; "even if she's been really, really ill she still believes that if she lies down and stays in bed all day that is where she's going to end up". It was an expression of their limited sources of bargaining power in the household and inability to garner the resources of supportive kin to take over when they were sick. For many married women, the primary route to release from everyday activities was through having a strong relationship with a husband who would advocate with senior family members on their

behalf. Nasreen, for example, was unable to secure sufficiently strong ties with her husband that he would stand up to his father on her behalf; “he could not say anything for his father”. Safia’s husband ganged up with her mother-in-law and blamed her for eating sweet foods when she claimed to be suffering from fatigue as a result of her diabetes, leading her to self-limit her claims to the sick role.

They’re all like oh you must have had a bit of chocolate today, you must have had that piece of cake that was in the kitchen or something, you must have had a biscuit with your tea... they’re like oh, we won’t be buying that again will we?... So that’s why I would be just like ok, just carry on, not even going to be bothered talking to you about it or anything like that.

Safia [female, 25-29 years, long-term condition]

Women’s performance of *sabar* and reluctance to take on an overt sick role related strongly to their power to command release from duties and attention from others, and to their access to alternative sources of recognition and status. Many of the female informants persisted with and were considerably ambivalent towards relinquishing their everyday roles (a topic that I discuss further in Chapter 8). Maintaining everyday roles was a way of maintaining valued roles and securing ‘centrality’ in their households. Nasreen, for example, felt that she had been exploited during the years of caring for her father-in-law; made to keep working on behalf of others and put her health second, and now felt that it was time for her to be entitled to some rest. She was drawing on the ‘patriarchal bargain’ (Kandiyoti 1997). She had played her part as a daughter-in-law, and it was time for others to give her attention; presenting her family members with the reciprocal logic of claims and obligations, power and responsibility.

From the family I want them to realize that my body has slowed down. I think I need rest. But I realised this when it was very late [starts crying]... I feel that I have used myself a lot. A lot... people have also used me... I feel bad that I didn’t take care of myself. When everybody else was thinking about themselves then why I didn’t think about myself? If I used to get tired and wanted to rest then I should have done that.

Nasreen [female, 45-49 years, long-term condition, translated from Urdu]

The corollary of women’s expertise over domestic roles was that men were often unable to take control of aspects of domestic life for which they were reliant on female labour. The naturalised, taken-for-granted constraint on male involvement in domestic duties had specific implications for the recognition of the sick role in the context of implementing dietary recommendations. Many of

the informants had been recommended “English food” by health professionals as part of their routine of health management. However, the challenge that dietary change represented to individual tastes and family and ethnic identities could be sufficiently threatening that other household members would refuse to take the health condition seriously. Many of the male informants reported struggles with their wives over implementing dietary recommendations, which took on a gendered dimension. The middle-generation women in the households were usually responsible for planning and preparing meals, and long-term sick men had to negotiate dietary change alongside “the cook”. If “the cook” took the health condition seriously, this meant preparing a separate meal for the long-term sick person or changing the diet for the entire household, and risking complaint. The struggles over food sometimes took on misogynist, classist qualities, as women’s resistance to implementing dietary changes was blamed on their lack of education and greater attachment to the culture of “back home”, which was said to make them narrow-minded and inflexible in their cooking. Women were thus made blameworthy for the men’s ill-health.

It's what they want... the chief who does the cooking, that has to be the one that has to be changed, the diet and everything. You know, what's the use of having a diet for, you know, just for me, the rest of the family just still eat red meat all the time. It has to be changed. And in a way we have, we've cut down on red meat now. So you have your chicken, you have fish and stuff. But again it depends on if she could speak slightly better, cookery books, you pick something say "yeah we could do that", something would happen, but at the moment... She does exercise, cook something new, but it's limited. So again, it's education.

Rauf [male, 50-54 years, long-term condition]

The indispensability of breadwinning roles also influenced the propensity to take on a sick role. The safety net provided by welfare benefits meant that in principle nobody should have been forced to remain at work beyond their capacities. In practice, however, this was contingent on socio-economic position, financial responsibilities and a constellation of other factors (I discuss this topic further in Chapter 7). Asif, for example, expressed a firm aversion to taking on a sick role, which was bound up in his desire to maintain an active identity as a “disabled person”; the sense of pleasure and fulfilment that he got from his job, which was skilled and professional; his dislike of dependence on state welfare – which he said was tantamount to “putting your head in the sand”; and the fact that he was the eldest male of three brothers and primarily responsible for the financial maintenance of his household.

I know visually impaired people who are articulate, but they would rather be on benefits. "I wanna sit at home, I've got nothing to do at home, I can't do anything. I will let the world rule my life and I'm quite happy on my £150 a week" and so on and so on. I've got a bit more, well I think it's the added thing of the responsibility. Family responsibilities, and so on. I mean I've got commitments. I've got three children now and I've got to look after them. So I mean technically I can't afford to stop working. So you know, you get on with it.

Asif [male, 30-34 years, family member with own long-term condition]

More commonly, employment was not as rewarding as it was for Asif. The majority of long-term sick people who were still at work were actively suppressing their symptoms and resisting the sick role due to the burden of their financial needs (*majboori*) and their indispensability to the household. Some of the informants who were resisting a sick role were earning a living under highly prejudicial circumstances which ultimately compromised their health in the long term. Naseem, a widow and breadwinner, forbade herself to take any leave off work because she was living "hand to mouth" and paying for the mortgage single-handedly. The extent of *majboori* (financial imperative) thus conditioned the degree of ill-health that would be endured before a person took on a sick role.

I don't know how much longer I can keep on with all my aches and pains. Maybe I'll retire in a year or so, stop working but I don't know. Let's see what is written in my kismet (destiny), lets see what I can manage with my aches and pains.

Naseem [female, 55-59 years, long-term condition]

5.6. Negotiating sickness in the *biradari* (extended family) and *maashra* (society)

Negotiating a sick role in the wider society was problematic. In some contexts it was important for the informants to have their ill-health legitimated by others. Individuals who believed that their ill-health was not recognised by others felt that they were accused of personal failings such as laziness, malingering or attention seeking; they sometimes needed to claim a public sick role and be exempted from their everyday duties and expectations.

When I ask people for help they don't want to help me because they don't know what's the problem... They say she is younger than us, she should help us, why is she asking for help. There is sometime I am having problem. Relatives they know the problem but strange people they don't know the problem, it's difficult to describe to them.

Amina [female, 35-39 years, long-term condition]

However, becoming openly known as a “sick person” (*mareez* or “patient”) was equally problematic, conflicting with their own expectations and self-identities. The importance of maintaining a veneer of normality in social relationships was well expressed by Yasin, who, like many of the informants, performed his sickness differently before “outside people” than he did with his “own people” at home, resisting the sick role in more public arenas.

My wife goes, I've noticed that in you. When you're amongst other people, you're alright. I dunno, maybe it's like, I dunno, instantly a show comes on, you know like a front comes up. And I'm, like, I'm alright. But as soon as you're back with your own people, you know, your own family, the original one comes out. The pissed off man.

Yasin [male, 30-34 years, long-term condition]

5.6.1. Stigma

The informants were concerned about other people being able to identify their ill-health from their physical appearance, particularly due to the yellowing or darkening of the skin or the appearance of dark circles under the eyes (*halken parhee hain*), which were also considered to be signs of moral wrongdoing; hair falling out; and above all weight loss, which was the most worrying of all. Sick people were marked by being *kamzoor* (weak) or *sooka* (dry) or having “lost their health”. The informants were troubled that strangers would comment upon their appearance, which was said to be a particularly Asian thing to do. White people supposedly did not remark upon such signs and would even avoid talking about them (see also Sachs 1995). The public scrutiny of their demeanour and bodily appearance could make long-term sick people feel objectified, and it could feel somewhat oppressive – although they also took part in doing the same to others, and it was intended as a gesture of sharing, love and concern.

You know people are so rude they stop and say what's wrong with you? Sometimes Asian ladies they know me, they're not my friends but they see me sometimes with my daughter or my granddaughters... What's wrong with you? Why are you walking like that?

Mumtaz [female, 50-54 years, long-term condition]

In contrast to the commoner conditions of diabetes and heart disease, it was extremely important for the informants to conceal any hint of mental illness, which was particularly stigmatising (see

also Katbamna, Bhakta et al. 2000). People with mental illness usually hid their symptoms from others rather than actively claiming a sick role. Umbreen used to restrain herself from doing her obsessive-compulsive “habits” in front of her mother and waited until she was alone before she would allow them to rush out all at once, fearing that she might end up in a mental hospital. As Waxler has also observed, mental illness conferred a very long-term, irreversible form of the sick role (Waxler 1977; 1980). People would be labelled as mentally ill long after they recovered from the medical signs of the condition.

If I see my family, I talk to them normally, it's alright, they'll have a normal conversation with me but at the end of the day, like they have this – I've been in the hospital, do you understand? I've been there, I've been in a mental institute. They're going to think that.

Guriya [female, 30-34 years, long-term condition]

The accounts were somewhat in keeping with Molloy and colleagues' study, which found that stigma and concealment were heightened among disabled South Asian people compared with their White counterparts. The authors suggest that South Asians confer the stigma of disability more readily to other family members, who are just as contaminated by their association with the source of impairment as the disabled person, especially when the condition is believed to be inherited (Molloy, Knight et al. 2003). The accounts are also consistent with the argument that South Asian concepts of personhood are relational and socio-centric (Dumont 1967). However, as I discuss further in Chapter 8, the force of stigma depended on the strength of existing relationships and the interests that other actors had in maintaining strong ties with that family. The ill-health could become irrelevant, or equally, it could be used as grounds for exclusion.

They [relatives and family friends] were in that frame of mind where they're having that taboo subject where they're oh, we don't want to talk about mental illness or, let them keep themselves to themselves. I mean, one of my cousins made a very er, very very erm, disgusting remark. It's like, if one of the family got a cold and that, it's obviously a viral air disease. Even the person next door's going to get that. But you don't then say, the father's got it, then I think all the kids need to be checked out.

Ismail [male, 35-39 years, family member]

5.6.2. Gossip

Pakistani society (*maashra*) was experienced as a double-edged presence in the informants' lives. It was clearly fulfilling and supportive, as demonstrated by the informants' desire for sociability and the extensive help they were able to garner from their social ties. In some circumstances, the ties of kinship-come-friendship in the wider society could be preferred to those of close family. Sayeeda, for example, had learnt not to discuss her problems with her family, as the repercussions were potentially too great, and only discussed her issues with the other women at her exercise session at the community centre: "I never miss it, I mean I really enjoy it. I think I work some of my feelings out, have a talk with some of the women on an impersonal basis... you can talk like no worries they're not going to come and tell your family that look she says this, they don't know my family".

Simultaneously, however, the *maashra* was also full of negativity and enmity. The female informants were particularly averse to sharing information about their health conditions among the wider *biradari* and community due to their concerns about gossip and backbiting (*chuglee* and *gheebat*) which were said to be a characteristic weakness of Pakistani people. Gossip was universally perceived through a misogynist and classist gaze, and associated particularly with the *Valdas*. Khalid complained about "women who are uneducated and do the squealers – all the backbiting, gossiping about who was seen doing what with who. They've just got no brains, they don't think. They're *jahil* (backward)". The increasing rivalry and competitiveness in the Pakistani community heightened the need to conceal ill-health. Domestic problems, including long-term ill-health, provided a platform for differentiation in status between households, and revealing them was therefore subject to normative pressures. In such a community, the informants said, one could not trust anyone; any information revealed concerning weaknesses might be turned around and used against oneself, including information about something as unfortunate as ill-health. Indeed, many of the women defined the success of their coping in terms of whether other people could tell that they were ill or not. Nasreen's account resonated with many of the others: "there are many people who do not know that I have such a severe eyes problem. I can hide it very well."

I don't discuss my household problems with anyone, I don't even speak about it in front of my bhabee (sister-in-law). If you tell people, it's like you're naked [lifts up her kameez to emphasize the point]. Your secrets come out. You lose respect if you tell others about what's going on in your life.

Iram [female, 50-54 years, long-term condition, translated from Urdu]

The resistance to talking about long-term ill-health also had emotive, structural and pragmatic grounds. People who were morbidly preoccupied with their ill-health or talked about their misfortunes too much could find themselves gradually abandoned by their family and friends, who began to find their company tiresome and difficult. Mehek mused that “I talk about my illness all the time so maybe they get fed up...”. Naseem, a widow, would not complain about her own aches and pains before her family members, unlike her sister-in-law Fatima, who was famously *chiri-chiri* (irritable) and complained non-stop about her heart condition and arthritis. Naseem felt that she herself could not afford to complain as much as Fatima complained. If other people were to be as irritated by her as they were by Fatima, the support she could expect from her family would wane, and her future would be vulnerable indeed. As such, the primacy on concealing ill-health reflected the extent to which the informants’ interests were vested in maintaining their centrality in their relationships with family and community, their *izzat* (honour or status) and their reliance on informal claims.

Fatima is always saying “I’m so ill I’m so ill”. I say to her “we are all ill!” ... She has always been like this and that is why nobody wants to be with her. If she comes and complains and makes a face and shouts at the children and fights with the people then nobody is going to invite her to their house.

Naseem [female, 55-59 years, long-term condition]

Feminine ideals around not revealing illness, not complaining and sacrifice were used as grounds for judging among individuals. Women who did *sabar* were praised, whereas women who talked about their problems were criticised and suspected to be morally disreputable. Often, ill-health was only revealed to a limited set of close friends or trusted individuals. Ayesha felt that her mother had benefited from sharing her health-related problems with her sister: “they both have health problems actually so it’s brought them together because they’re both suffering from the same types of problems... now they have a lot more in common than when they weren’t suffering from anything”. However, even then the onus on concealment was strong: “they [parents] couldn’t hang their dirty laundry out in public, it’s hard enough for her to talk to her sister about little things”. Some of the informants saw the normative pressures against sharing experiences of ill-health as damaging, illustrating the congruence of biomedical discourses around stress and social support with the informants’ own understandings. Nonetheless, the reputation for *sabar* and stoicism brought dividends; they were able to claim moral high ground and were seen as

respectable individuals in the community. “I do not advertise my problems”, said Nusrat pointedly, “unlike Naila”.

There are people who share their problems. But I have never done so. It is something like family prestige. Sometimes I used to think to share but there was so much of family pressure... then there was my illness...

Nasreen [female, 50-54 years, long-term condition, translated from Urdu]

Finally, there were a number of female informants who did not buy into the shared norms around *sabar*, talked openly about their problems and suffered the small-mindedness of people who judged them as *batoonee* (chatterbox). Mariam, for example, shared her problems fairly indiscriminately with “outside people”: “with me, I talk to everybody about my problems. I don’t know how many people know about my problems but I can’t keep my problems to myself”. However, the trade-off was that she was widely seen as somewhat *besharom* (shameless). Mariam’s free talk did, furthermore, impact on the resources she could garner through her social ties. The husbands of two of Mariam’s closest friends, upon whom she relied for diverse favours such as childcare and putting her up whilst her house was being refurbished, had effectively banned their wives from letting her come round. The husbands considered Mariam to be a bit of an *awara* (loose) and did not want their wives to associate with her. *Awara* is a multi-faceted term encompassing freedom and moral looseness that carries negative connotations when applied to women; as Usman said, “a woman ought to be refined or a bit subtle and not do *awaragardi*, like if she speaks too much on the phone, goes to her friends’ houses all the time, or wastes time outside going to the bazaar or going to the cinema”. Women who were independent and did what they liked were not, therefore, necessarily the strongest in a system predicated on *ikathe* (togetherness), in which women’s interests were strongly vested in their centrality to the family and community.

5.7. Conclusions and implications

This chapter examined the social process of becoming long-term sick in relation to the concept of the sick role, which brought out the *practical* consequences of long-term ill-health, the informants’ internal struggles and contradictions between “taking control of” the health condition and succumbing to their difficulties and reduced capacities, and their concerns with how long-term ill-health was affecting the balance of power in their interactions with others. It showed that

stepping into the full social role of a *mareez* or “patient” was not determined by the disease course alone, but rather depended on the wider context of their lives.

Interactions with other people were an important influence on the process of becoming long-term sick. The legitimization of subjective feelings of ill-health depended strongly on health professionals, as well as access to treatment and potential relief from suffering. The informants’ dependence was accentuated by their relative powerlessness and marginality, which often led to unsatisfactory treatment outcomes and potentially deepened their preoccupation with ill-health. The home and community were other key arenas shaping the experience of ill-health. Indeed, how ill-health was recognised in the home emerged as, in some ways, *constitutive* of its social reality. Within the home, the negotiation of ill-health was embedded in socially-defined hierarchies of power. Access to the sick role was mediated by ideologies surrounding generation and gender and appropriate household roles. Feminine constructions of the sick role in terms of sacrifice and silent suffering had particular significance in offering women a way of negotiating their interests within the limits set to their gendered power, and can be seen as a creative, emic expression of agency. In the wider community, there was an overwhelming desire for concealment. Indeed, many of the informants defined ‘coping’ in terms of nobody being able to tell that their families were affected by ill-health. However, concealment depended on the extent to which the informants’ interests would be threatened by publicly claiming a sick role, and on their reliance on ties with family and community. Within limits, therefore, the informants were able to reproduce or resist norms and values surrounding the sick role in accordance with their own interests.

The diverse findings of this chapter emphasised that the impact of long-term ill-health was embedded in the individual’s wider situation or context, particularly the ‘local worlds’ of home and community. The following chapters pursue this question and explore how the wider context of the informants’ lives shaped the impact of long-term ill-health on their prospects in employment (Chapter 6); their prospects for getting by and managing the economic costs of long-term ill-health (Chapter 7); and ultimately the capacity of the households to reproduce themselves on the day-to-day and inter-generationally (Chapter 8).

Chapter 6: Production

ghareeb mein atta gila nahi hota

when you're poor you can't afford water to wet the flour – Urdu saying

6.1. Introduction

This chapter examines the impact of long-term ill-health on 'productive' – namely income-generating – work. In the majority of cases this meant wage labour, upon which households in the UK have been almost completely dependent since the 19th century (Pahl 1984; 1988). The quantitative analysis in Chapter 3 found that long-term sick Pakistanis were one of the groups with the lowest levels of paid employment overall. However, it also found that the associations between long-term ill-health and employment were modified by age, gender, qualifications and housing tenure. This chapter builds on these insights, and examines the impact of ill-health on productive work in the context of the informants' labour market positions. First, I examine whether the informants were able to maintain employment after the onset of their long-term health condition. I then explore the prospects for [re]gaining employment for those who left work.

I analyse the employment prospects of the long-term sick informants in the context of the social relations of work. The chances of retaining and (re)gaining employment were constrained by the types of occupations and industrial sectors prevailing in the economy of East London, and as such were contingent on the processes of migration, incorporation and economic restructuring. Chances of maintaining employment were influenced by the unskilled nature of many of the informants' occupations, reflecting "the particular dependence of the poor on their own bodies" (J. Harriss 2006) (p.7); the specialisation of the informants' skills and the ease with which they could be replaced; and the weak contractual elements of job protection as stipulated by employment law. Moreover, job retention was also influenced by informal social claims that were embedded in the structure and hierarchy of the workplace and negotiated piecemeal. The trust held in social relationships in the workplace was an important resource in containing the risk and uncertainty that was introduced by long-term ill-health for employers or clients. As Pinder suggests: "what disabled people are faced with at work is the task of establishing trust or repairing trouble, which in turn highlights the differential ability of individuals to 'run with' ambiguity and disturbance, and of organisations smoothly to dispose of it" (Pinder 1995) (p.607).

The informants' employment prospects were also influenced by cultural ideologies surrounding the indispensability and appropriateness of employment, which were embedded in relations of

gender, generation and position in the household – the informants’ ‘local worlds of experience’ (Kleinman and Ware 1992). However, the role of cultural norms and values was not merely one of constraining certain individuals. The informants did not merely re-enact social norms, but interpreted them in accordance with the stakes at hand, in the context of local arrangements of power. As previously, I use the concept of social practice to explore how the informants engaged creatively with employment within the limits set by the racialised labour market and cultural context.

6.2. The labour market position of long-term sick Pakistanis

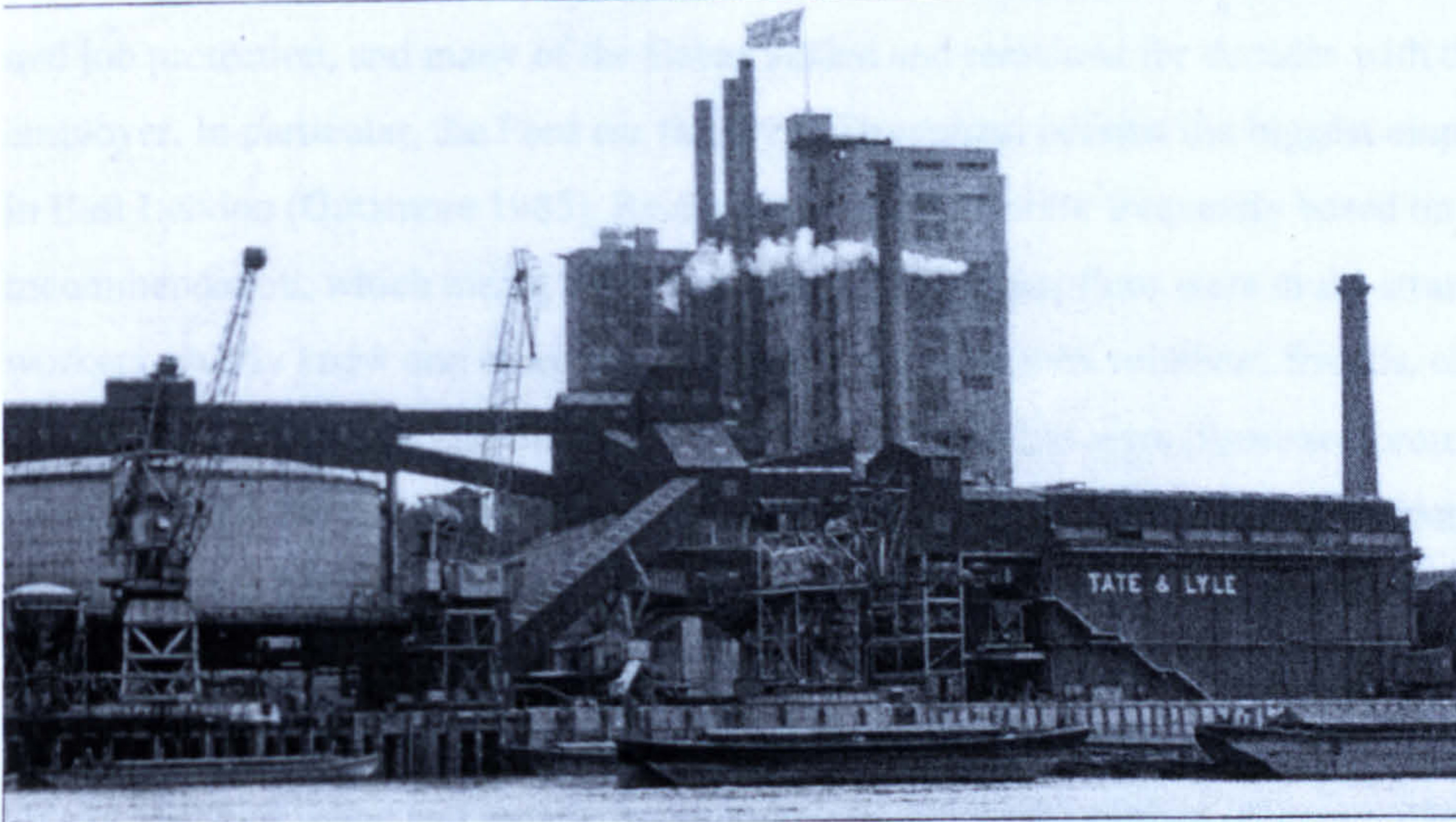
The impact of long-term ill-health on employment was contingent on the informants’ existing occupations, and the types of employment opportunities that presented themselves in the local area. As I discussed in Chapter 4, the labour market of East London has seen enormous changes over the 40 odd years that it has had a significant Pakistani population. The economy of East London has transformed from being the industrial heartland of the South-East to an area of industrial decline, in which the slow growth of the service sector has not quite managed to provide jobs for a still predominantly working-class and low skilled population. The consequences of long-term ill-health for paid employment are therefore analysed in the context of the informants’ existing positions within the labour market of East London.

6.2.1. Manufacturing jobs

The long-term sick Babas were largely out of employment and many had been so for up to two decades. Health conditions among the Babas were common. Indeed, many of them attributed their current state of ill-health to industrial accidents and years of heavy manual labour done over long and unsociable hours, and in poor working conditions. Sadiq, for example, had been suffering from a slipped disk dating back to his days working in the cool room at the Ford motor factory in the early 1970s.

I was thinking in my mind, because that time I was doing very heavy job – take something from the rack, a lower high racks, I had to make 20 30 40 pound sometimes 20 pound lifting...Sometime I take something here, lift it up, I go down and have problem with the back as well. So I was thinking something I done silly at the work, and that’s why I got the back pain.
Sadiq [male, 60-64 years, long-term condition]

Plate 11: Tate and Lyle sugar refineries in 1967. Most of the early Pakistani labour migrants found work in small-scale factories and workshops run by Jewish or Asian patrons in Aldgate and Whitechapel before discovering more favourable terms of employment in the large factories surrounding the docks.



Source: London Borough of Newham (2002), p.24.

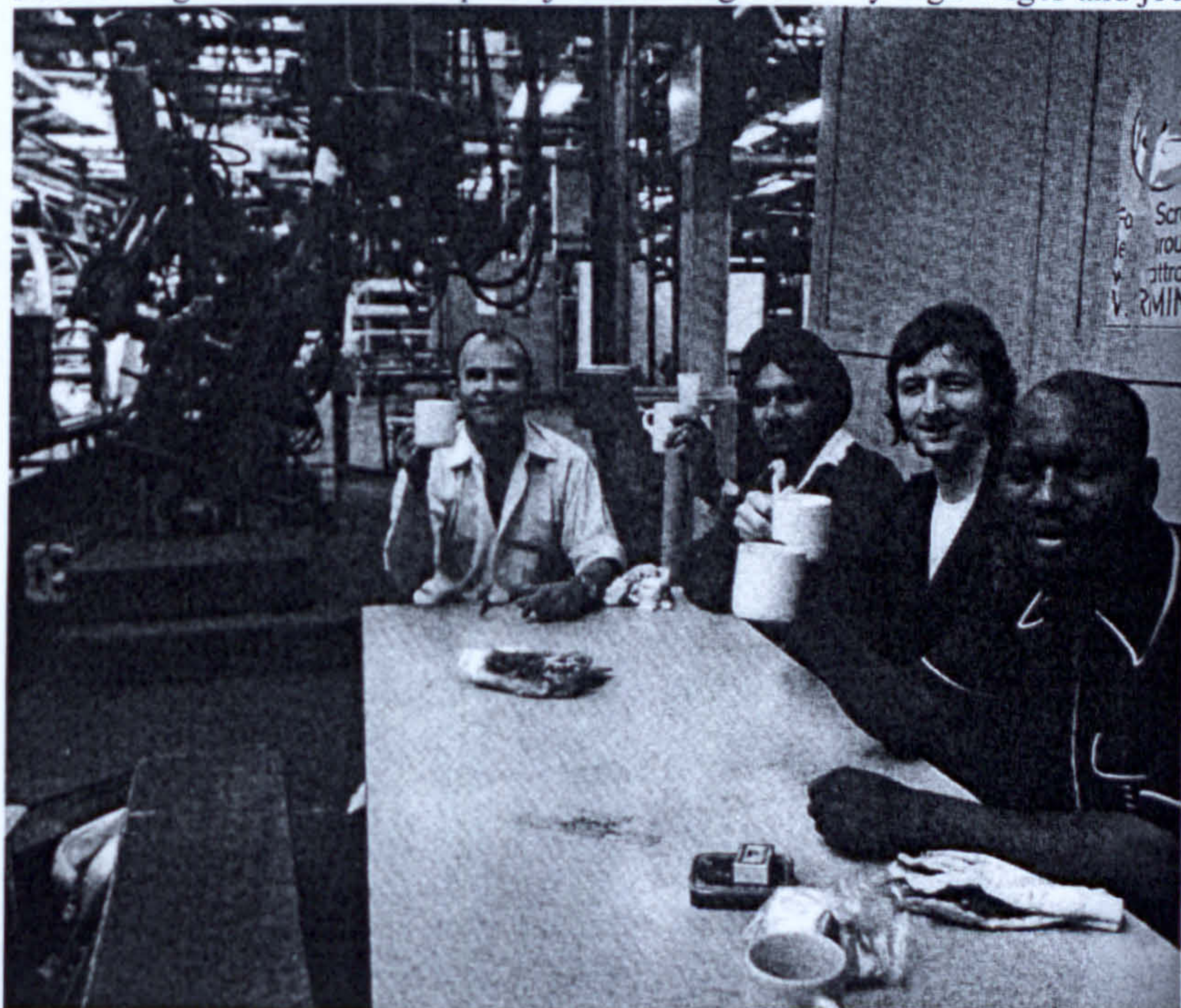
Plate 12: Pakistani flour mill workers recovering in hospital in West Ham, 1960s. The men were recuperating from a near-fatal lung infection contracted due to the dusty atmosphere and poor health and safety conditions in the flour mill. Working conditions endured in the early years of settlement in East London contributed to the high levels of premature long-term ill-health among Pakistanis today.



Source: author's own.

In the early years after migrating to the UK the Babas switched frequently between manufacturing jobs, following information and contacts provided by relatives and friends, and exploring different options for work. However, jobs in large factories offered relatively good pay and job protection, and many of the Babas settled and remained for decades with the same employer. In particular, the Ford car factory at Dagenham became the biggest employer of Asians in East London (Gutzmore 1985). Recruitment practices were frequently based on personal recommendation, which meant that relationships on the shopfloor were multi-stranded – Pakistani workers usually knew one other simultaneously as colleagues, relatives, friends, class-fellows and neighbours (see Brooks and Singh 1979). Some of the Babas were dismissed promptly after the onset of long-term ill-health; it was easy to replace workers in low-skilled occupations. The eighteen years Bashir spent working as a security guard provided him with little security: “my GP gave me 12 weeks rest before the gall bladder [operation], and they chuck me out. They said they need me, but if I don’t come tomorrow they will employ someone else”. However, others were able to take sick leave and remain in employment. Under the regime of accumulation in the 1970s the bargaining power of the unions was strong; many large firms had adopted conciliatory schemes to contain conflict between labour and management, and jobs were relatively protected, including entitlements to sick leave, sick pay and pensions (Cohen and Kennedy 2000).

Plate 13: Workers on a tea break at the Ford Motors in Dagenham, 1978. Although highly publicised legal cases have been brought against Ford Motors alleging racial discrimination, for many Pakistanis working at Ford during the 1970s was a ‘plum job’ offering relatively high wages and job security.



Source: Gilroy (2007), p.258.

The Babas drew informally on the social resources they had at work. The long-standing and personalised relationships that many of the Babas enjoyed with their largely White supervisors were a valuable form of 'bridging capital' (Putnam 1993) that allowed them to secure their jobs. By contrast, relationships between workers on the shop floor often presented a form of 'bonding capital' (*ibid.*) cemented by shared ethnicity. Co-workers informally traded duties and allowed sick people to do the "light work" (*halka kam*). Co-ethnic ties between workers provided "understanding": the sense of trust and obligation that allowed them to make adaptations to their occupational role and remain at work despite incapacity and frequent absenteeism. As Sadiq put it, "my supervisors knew me", because of which it was understood that he was not to do "heavy work". The following quote from Razzaq illustrates how the "understanding" he had developed with his White "governor" managed to contain the problems raised by his long-term ill-health.

My boss was a good man, he was good. Sometimes if I had to round the doctors or hospital then I would, that's it.

K: What did your boss use to say about that?

He was alright, he said won't think if it's once a month or something, so it doesn't make any difference. He goes if it's busy and you can't finish it off, you can finish it the next day. And that's it.

Razzaq [male, 50-54 years, long-term condition]

Furthermore, the Babas were not passive in the face of disagreements with managers and supervisors. Most of the Babas were paid-up union members, and the poor track record of the unions in representing the interests of Black and Asian labour had a number of Pakistani men to become prominent union leaders (Newham Monitoring Project 1991). The Babas knew their rights and used their understandings of their employer's obligations to claim their entitlements, enlisting GPs and social services to advocate on their behalf. Sadiq, for example, had invested part of his wages in a sickness insurance scheme offered by Ford. Although the insurance company initially refused him his payment due to his absenteeism, he eventually secured it, arguing that "that's why I paid so much, because any time I need I can get the money from you". Indeed, the Babas enjoyed more job protection in the face of long-term ill-health in the Ford factory than their contemporary counterparts doing equivalent low-skilled jobs in the service sector. As Yunus said, "sometimes I cry because I had such a good job".

Plate 14: Black and Asian workers striking Ford Motors in Dagenham, 1970s. Black and Asian workers took part in many industrial disputes as well as fighting racial discrimination and physical harassment at the workplace.



Source: Newham Monitoring Project (1991), p.27.

The inexorable decline in the health of the Babas coincided with the decline of the manufacturing sector in East London. In many cases the eventual prompt for leaving employment was the contraction of the industry and the ensuing redundancies, job losses, down-sizing and factory closures, rather than a deterioration in health status. In a shrinking sector, the long-term sick Babas were the first to be pushed into taking redundancy, being so restricted in the tasks they were capable of doing. For those whose claims to their jobs were personalised, based on the understandings they had negotiated carefully with their supervisors and managers, the chances of finding new employment were slim, particularly in a declining sector and during a recession.

I used to work up there in Ford motor company. That place been closed down 1985 and lot of people got a job in different department. I went to see the personnel manager before I leave the Ford. He says we can offer you a job in a different plant, in the other plant. But after the operation [i.e. his back operation] you get light work in here, because we know you are working since 69 with us. And we don't give you guarantee you get light work up there. The best way, I advise you take your money, whatever you get. So since 1985, I left Ford.

Sadiq [male, 60-64 years, long-term condition]

The governor died, the person I was working for, he died. And they closed the factory and I couldn't get a job after that.

Razzaq [male, 50-54 years, long-term condition]

After leaving the factories, some of the Babas tried to set up their own businesses, either in Pakistan or in the UK. The transnational connection was an important resource that the Babas drew upon during the period of industrial decline, although the economy of Azad Kashmir also presented few possibilities for lucrative enterprise (see also Kalra 2000). Whilst most commentators have examined the crumbling of the 'myth of return' in relation to economic constraints in Pakistan (see e.g. Anwar 1979) the ageing and deteriorating health of the pioneer migrant generation and their reliance on the NHS were also very significant factors. In many cases, the healthcare infrastructure in Pakistan was simply inadequate for meeting the complicated medical needs of the Babas and Valdas. Naseem and her husband got diarrhoea, piles and anaemia, and became so ill that a Pakistani doctor was moved to ask "how is it that you are still standing and walking around?"; by the time they returned to London she was so weak and wan that her brother greeted her at the airport with "what happened to you?!". More often than not, the Babas spent a few years unsuccessfully attempting to set up a business, and then returned to Britain. Sadiq tried to set up a timber firm with his father in Azad Kashmir but it proved unprofitable: "my father's telling me the story about the government and this tax and this, and he said it's best you do the business back home, back to England". For people who were long-term sick, the low levels of welfare benefits made it difficult to raise the capital needed to get involved in business. They had usually already used up whatever savings they had; they had few assets on which to take loans; and finally, their health limited the range of endeavours they could be involved in. For many of the Babas, economic restructuring was the start of a prolonged spell of worklessness.

The involvement of the pioneer generation of migrant women (the Valdas) in factory employment should not be ignored. There were a number of urban Punjabi-origin Valdas who had arrived in the UK in the 1960s and 1970s who were in formal employment on shopfloors of feminised sections of the garment, footwear and catering industries (see Saifullah-Khan 1979). With some pride, Yasmin recalled that, in the early 1960s, for her husband's weekly wage of £12, she earned £6 from a garment factory, which she spent on the housekeeping and the children. As for their husbands, the onset of ill-health usually sounded the last toll of the bell for paid employment for the Valdas. However, since the women were usually working fewer hours than the men, the final move out of work was more gradual. Moreover, the gradual reduction in hours of work could negatively influence their claiming of sickness entitlements, as they were inclined not to cut off completely from the employer but remain nominally at work on the off-chance that they would be able to manage work again at a later date. For example, Maheen attributed the pain in her feet to accidents that she had in the kitchen of the catering firm in which she worked. However, she did

not report the accidents within the three years required to claim her sickness entitlements, and was left defeated in her negotiations with her employers over sick pay. As she said: “they do respect me very much when I started cooking, they don’t want to lose me but they said the law is same for everyone. If it’s one week over three years, I can’t help you. Last one is I not reported, in hurry to come home”. Maheen’s misunderstandings with management contrast with the experiences of the Babas, and hint at the vulnerability of female employees and their greater reliance on informal claims to job security. Whilst “understandings” with supervisors were undoubtedly an important resource in negotiating ‘trouble’ at work, long-standing job arrangements could also create a low polarisation of interests between management and labour that could also encourage employees to accept prejudicial conditions.

Plate 15: Garment factory in East Ham, 2004. The survival of the garments industry in East London is largely due to its incorporation of ethnic minority labour, relying on low pay and cutting costs. Asian people have been running garments factories in East London since the 1950s.



Source: author’s own.

6.2.2. Self-employment

In the same way that economic restructuring framed the experiences of the Babas in manufacturing, similarly, for the Babas and Kakas who started their own businesses, long-term ill-health was a shock that coincided with the recessions of the 1980s and early 1990s, compounding the problems of low demand and contracting markets with increasing absenteeism.

Self-employment was identified as a very stressful occupation and linked to self-exploitation and ill-health. In the accounts of the self-employed informants, bankruptcy, unemployment and the onset of ill-health were inseparable. Yusuf, for example, attributed his heart condition to the stress of losing his business.

My own health suffered. I had a triple bypass in 98, and I had a very severe accident and nearly passed away in 96. I was on crutches for 9 months. It was all in relation to stress. I was a successful businessman from 1978 to 1990. I made just one mistake – I bought some dry-cleaning shops in 1990. Then there was the recession in 93. Seven hundred people were going bankrupt every week then. I went bankrupt in 94.

Yusuf [male, 55-59 years, long-term condition]

Self-employment was the factor that most differentiated the fortunes of the long-term sick informants. It could be a form of livelihood that was quite compatible with long-term ill-health. For the Babas who had set up successful businesses and risen through the echelons of enterprise to manage large portfolios, the everyday hands-on work required could be relatively minimal. Kanwal's father, for example, owned a construction company, some 17 shops on lease-hire and a lot of property on the buy-to-let market. Although distraught about the return of her father's cancer, she wasn't too worried about what would happen to her parents financially, as she knew they would never lack for money: "now that the businesses are all set up and done he doesn't have to lift a finger, he's got a lot of time on his hands". Established businesses provided a dependable and indefinite source of income into the future, which could be relied upon without much day-to-day involvement or physical work.

In smaller businesses, self-employed informants were often able to draw on family labour to substitute for themselves during periods of ill-health: the family has been identified as a key 'ethnic resource' in the success of Asian entrepreneurship in UK (Werbner 1990a; Metcalf, Modood et al. 1996; Basu and Altinay 2002). The ideal of mutual assistance and gendered power dynamics are summed up in Rasheed's request to his wife Naseem to leave her administrative job and help him to run his business after the onset of his heart condition: "what's the point in working for outside people when your own people need you?". Marginal family labour was very important in tiding a business through periods of sickness. Although it was frequently to the cost of the individual, it is important to note that the appropriation of family labour was not inevitably experienced as exploitation. Many derived a sense of self-esteem from helping out ailing family members. It was supported by ideologies of family duty, obligation and unity. The moral status

that could be derived from such acts of filial duty is captured by Kanwal's statement that "it's something that I felt I had to do as well as wanted to do, because obviously this is something that dad said, never let anybody else step in" – despite the fact that filling in for her father coincided with her A-level exams and led to a near-complete rupture in her ties with her father's brothers, who objected to her involvement on the grounds of her being "wet behind the ears" and female.

Plate 16: Shops on East Ham High Street, 2004. The 1970s and 1980s saw a widespread shift of Pakistanis into the property market and self-employment.



Source: author's own.

Although Pakistani families have been portrayed in the literature as corporate groups in which: "each member of the household is expected to make a contribution, in accordance with his or her ability, to what are perceived as shared objectives" (Werbner 1990a) (p.58), the commitment to enterprise was actually highly divergent within families (see also Ram, Abbas et al. 2001a; Sanghera 2002; Anthias and Mehta 2003). Filling in for sick family members was replete with tensions and resentment – although the resentment was difficult to articulate as, ostensibly, the person with the health condition was not sick on purpose. As Ricky said of his father, "it's not his fault". People with long-term ill-health could also claim potent moral authority over their family members (see Chapter 5). Eventually, however, there came to be a limit to the extent to which family members would provide unremunerated help without any certainty about the prospect of relief or reciprocation in the long-term. The Babas and Kakas often expressed concerns about the

“selfishness” that had infiltrated their families since the migration to the UK; the common complaint was that everybody in Britain had “their own life to lead”, “nobody has any time for anybody else”. There were concerns that the younger generation were no longer interested in going into the family business, being more interested in pursuing further education and professional employment, or being *laperwah* (irresponsible) or *lafungas* (good-for-nothings). In the long term, therefore, there were limits to the extent to which family labour could substitute for a sick proprietor.

I had nobody else to help me run it. I mean, I've got my wife's uncle, but he's got his own things to do. He was going to open half a day here, half a day there, try to do his best, you know, but he couldn't do more. I couldn't expect him to do more than that. You know, he's got his own life.

Yasin [male, 30-34 years, long-term condition]

In addition to the problems of mobilising family labour, the resilience of a business in the face of long-term ill-health was very much dependent on its size and level of establishment. For many of the informants self-employment was “a sideways shift from lumpenproletariat to lumpenbourgeoisie” (Aldrich, Jones et al. 1984) (p.191). In such cases, the economic impact of long-term ill-health could be even more decimating than for individuals who were paid employees. If a self-employed person were absent from work due to ill-health, they simply would not earn, and would suffer an immediate loss of income. As Yasin appreciated, the financing of small businesses was hand-to-mouth: “obviously, if you're not opening, then nothing's coming in, and you start going downhill”. Income from self-employment was often low and unstable, requiring the informants to dig into their personal savings to cover overheads for the business, take credit to smooth peaks and troughs, and divert working capital for family consumption to tide them through periods of sickness. As a consequence of absenteeism, the reputation and credit-worthiness of the business would suffer.

Many self-employed people have not taken out sickness insurance. Moreover, as Hossein's account demonstrates, self-employed people were not entitled to any sick pay from an employer, which meant that there was no source of income to tide over the family consumption. Whilst waiting for their benefits applications to be processed, they relied upon their own savings and liquidated other assets. For example, after four months in hospital, Hossein had already been obliged to get his wife to sell their car so that she could meet her household expenses.

That was something I never really believed in, insurance. That's something I've never developed... I think you're much better off working for someone. Then at least you have a fall-back. Whereas if you're self-employed then you have nothing to fall back upon, it's just yourself. And you're never ever covered for all the eventualities. You never ever cover yourself – because when you're working for yourself, you're trying to save as much money as possible, and you tend to cut corners.

Hossein [male, 40-44 years, long-term condition]

For self-employed people, therefore, long-term ill-health had economic consequences beyond the loss of income and employment. Business failure due to ill-health could lead to considerable personal losses, compounding the problems of getting by on reduced income. The assets of the self-employed informants, particularly housing, were inseparably interlinked and bound up in the enterprise. As Werbner points out “housing is incorporated by Pakistanis into an overall economic strategy” (p.45), “as part of a multi-faceted enterprise or a complex economic portfolio” (p.42) (Werbner 1990a). Rasheed and Naseem, for example, put a number of entrepreneurial ventures against their house during the 1980s, which had to sell off at a huge loss when Rasheed developed a heart condition and eventually died. At age 60, Naseem was left with 15 years of remaining mortgage repayments, and she was understandably pessimistic about her chances of ever paying off her debts.

Thus, although self-employment offered the possibility for accumulation and becoming prosperous, for those who become long-term sick, it was also an insecure sector to be in. The lack of sick pay could drive sick businessmen who lost income due to absenteeism to attempt to recoup their losses by evading tax. As Waqar said, “in business there's no sick pay but if you can keep back your tax then that's another matter”. The lack of sickness protection for the self-employed – characteristic of the deregulated and flexible labour market of the UK – meant that informal economic strategies became a coping strategy to prolong business survival, rather than strategies of accumulation.

Kalra argues convincingly that increased risk is the most important characteristic of the British Pakistanis' shift to self-employment, in which individualism and competition are inherent (Kalra 2000) (p.180). In addition, I would emphasize that the risk had deflected from large-scale capitalists and the state and onto the informants themselves. They were in a sector in which uncertainty about health brought the risk of business failure and personal loss as well as lost income, with none of the sick pay that would otherwise accrue from employers.

6.2.3. “English jobs”

“English jobs”, as they were referred to by several informants, comprised professional, white-collar office work, particularly non-manual work in public sector institutions, as in local government, education and the NHS; and in the voluntary sector. Non-manual local state employment was opened up to Asians in the 1980s and early 1990s due to anti-racist activism and the introduction of equal opportunity policies, particularly in London and the South-East (Virdee 2006). As the term “English jobs” implies, jobs in these types of organisations involved an element of equal partnership with the ethnic majority in mainstream institutions. Many of the informants talked covetingly about “English jobs”, which were part of the formal, regulated economy and gave workers a minimum of legal rights to job security in the face of long-term ill-health. “English jobs” also offered “light work” which the informants believed they could reconcile more easily with their health conditions. The skilled nature of the white-collar work meant that employers were more proactive in seeking out adaptations to allow long-term sick employees to remain at work. Employers in such organisations sometimes facilitated access to technologies to allow the informants who had impairments and limitations to remain at work. The employees also had a higher level of commitment to retaining their jobs, and they tended to find more personal fulfilment from their work than the informants who were doing unskilled occupations.

I've got the screen enlarging stuff on my computer so you know, reading stuff or whatever isn't really a problem. I have a reader who reads stuff to me so if I get any letters or whatever then he will actually read stuff to me. That's paid for by Access to Work. When I joined [employer's name] it was quite a new scheme then, that was nine years ago. It was meant to be one of the governments' you know, flagship projects type thing but it was one of their best kept secrets I think.

Asif [male, 30-34 years, family member with own long-term condition]

Skilled occupations and jobs in public sector organisations offered job protection and higher rates of sick pay. Ubaid managed to keep his job for four years despite very high levels of absenteeism due to his diabetes: “they knew about my illness so they were quite helpful and understanding”. By the time he was eventually asked to leave, he was taking absences of up to three months duration, and working only four and a half months a year. The institutional stability of the organisations, and their relative robustness to wider macro-economic change, also provided job

security. However, when public sector workers were threatened with internal reorganisations and efficiency drives, long-term sick individuals were under greater pressure to take voluntary redundancy or early retirement, as their ill-health made them vulnerable as employees. Absenteeism also engendered feelings of insecurity which served to keep some of the informants at work even when they felt physically incapable of doing so. Liaqat could not trust his employer, and would struggle to work despite sickness, fearing that absence would result in him being sacked. Shazia felt the same, and seriously compromised the management of her health. It was, therefore, possible to remain in paid work; but the returns to employment might be extremely prejudicial to the employee.

Everything you do now, you have to care for in a year, I don't go more than 13 days sick. If I go more than 13 days sick then I get a big problem, then I go to the [employer's name] medical board [titters humourlessly]. They ask me the questions that why are you sick blah blah blah. // They say that I'm sorry, it's just our system you know, next time. But what can I do, you know? If I'm not feeling well, do they want me to die on the floor, working place in there? You know, the decisions they... humiliate now you know. Humiliation you know, that's what it is now. But I need to work, carry on now, you know heh heh [titters]... If you go again sick they sign down, because you are unfit to do the job you know, and they give the sack.

Liaqat [male, 55-59 years, family member with own long-term condition]

I can't afford to go for the scan [for ovarian fibroids] because I'm on six months probation at work. The people at work, they do love me but I've taken too much sick leave. In the last four years the time I've had off adds up to a whole year. If I tell work then I'll lose my job.

Shazia [female, 35-39 years, long-term condition]

Despite entitlements to sick leave and sick pay, some employees in “English jobs” also had to leave work. “Light work” could still be incompatible with conditions involving pain, discomfort whilst sitting, or the loss of mental capacities, such as concentration, memory, handling responsibility, effective communication or social interaction. Eventually they would be given early retirement on health grounds, and leave with an occupational pension. Rauf's employers, for example, did try to re-negotiate his work role, but were defeated by the extent of his incapacity.

After the stroke they sat down they said well, if you can find something we'll do something, but the things you want, you can't do the things. And then I tried to find something to do but problem is for me, if I can't write, it doesn't matter how much good you were, how bright you were, you

can't do anything about it. So I spoke to few people, and he said how about you talk about policy, but then still you have to give the reports, so I couldn't do that either. So, they're still trying to find a job.

Rauf [male, 50-54 years, long-term condition]

6.2.4. Low-skilled service-sector jobs

Temporary, casual, flexible, service-sector jobs, particularly in retailing, were an important element of the employment profile for younger informants; male and female, migrant and non-migrant. In part, this reflects the process of economic restructuring in East London and the gradual tertiarisation of the labour market, which has produced a supply of cheap, low-skilled service sector employment – what Lash and Urry refer to as “the MacDonaldisation of the workforce” (Lash and Urry 1994) (p.196). It also reflects low educational performance and discrimination, which served to keep the informants concentrated in the more poorly skilled and poorly paid occupations. The culture of flexibility espoused by such organisations meant that the employment of low-skilled long-term sick employees was precarious. Their contracts offered minimal protection for sickness, and labour representation did not figure at all in their accounts. Zafar, for example, had to entreat a local NGO, his solicitor, GP and urologist to advocate for him over what he called his “bullying problem at work”.

They said that I can't work fast like I used to... So that's when I went to solicitors and I told them and they're telling me you've got a very good case. But then later on they sent someone from head office, and I told him I can't take no more bullying... I cannot complete five tasks in four hours I just can't do it any more. I said your manager's like bully, big bullies their behaviour aint ethical, not this time. So things have calmed down because the urologist has made it clear they can't put a finger on me.

Zafar [male, 40-44 years, long-term condition]

With few exceptions, career trajectories were disrupted and fragmented, with frequent moves between organisations, and between unemployment and work. As Shamim said, “illness doesn't really affect people's careers because people round here don't have careers”. Ill-health was just one of a multitude of factors causing them to leave a job. The informants often perceived their jobs as inconsequential and felt little loyalty towards their employers in the long term. Afshan expressed a common sentiment: “it was only a job, I can get a job anywhere again”.

When I was in [retailer's name] to train me up for like one week, I think it was Christmas that time, then there was two weeks off then I didn't bother going back then. Then I just... I dunno, left everything I just... I done a few stuff in my life.

Naem [male, 25-29 years, long-term condition]

6.2.5. Undocumented work

The grey “cash-in-hand” economy was widespread, providing a route to survival for those who were most precarious in the labour market and a route to accumulation for a minority of opportunists. Undeclared work was undertaken in response to the low levels of benefit payments and high levels of debt, avoiding tax and national insurance contributions, and allowing income to be earned alongside welfare benefits. Zubia, for instance, ended up committing benefit fraud after her incapacity benefit was unexpectedly taken away. Due to her deepening financial problems and the delays in the processing of her application for income support, she was drawn into working cash-in-hand in a factory. This was later discovered by Newham council, and she was obliged to repay the £600 she had taken in benefits whilst working in the factory. People with restricted hours of work were similarly reliant on informal work, particularly the Freshies (students and asylum seekers).

Much of the informal work was undertaken for Asian (*apne*) employers, which the informants experienced as a double-edged arrangement. The deployment of co-ethnic ties was mediated by trust (*aitbaar* or *yaqeen*): “the evocation of moral bonds specific to members of the group and excluding outsiders” (Werbner 1984) (p.168). The multi-stranded relationships between co-ethnic employer and employee provided moral space in which to renegotiate the occupational role in the face of long-term ill-health. Shared ethnicity also engendered “understanding” that facilitated positive relationships with employers, colleagues and clients – what several informants referred to as their “comfort zone”, in which they could make claims of moral obligation and notions of reciprocity, drawing on an ethos of “looking after your own”. As Naem put it, “you feel you can rely on another person who’s the same background”; “I was enjoying the work... they were all Asian, that’s why”. For many of the informants, co-ethnic claims resulted in informal job arrangements. These could be under rather favourable circumstances, as for Afshan, for example, who was employed by a “family friend” who did not worry about her taking leave for ill-health.

I do have a job but I'm not actually going there. I've been working there since November and it's an accountant's firm. It's for a meat shop, they've got a little office downstairs with their own

accountant. So I'm just a little helper there, on the computer and the telephone calls. But they've given me this month off because I've had flu, and I think they said because it's gonna be Eid and everything, and they said look, I need to sort some stuff up and they said oh, is it – they're family friends. They've known me since childhood so they said you can have this whole month off.

They've given me paid leave.

Afshan [female, 20-24 years, long-term condition]

However, it is extremely important to dispel the view of co-ethnic labour as unproblematic (see Ram, Abbas et al. 2001b; Salway 2007b; Ahmad 2008a; 2008b). Many of the informants identified working for *apne* (our own) employers as exploitative, a phenomenon which was strongly connected with the opportunities for mistreatment created by the social relations of informal work. For long-term sick employees in the grey economy, ill-health entailed particularly poor returns to employment due to their vulnerability in the wider labour market. Rates of pay were predictably low, as employers could get away with giving poor wages given the employee's lack of alternative opportunities. Furthermore, undocumented jobs offered little security to those who were unable to carry out their work due to ill-health. Evidently, those who were under-paid or unfairly dismissed were unable to take any union or legal action because they had to avoid the attention of the authorities at all costs.

They chucked me out then – yeah they shopped me cos I like, I was like ill I kept going in and out of hospital that time... I had all this pains down the back and if I was moving stuff you know... I left [retailer's name] and then I went the next day and I go "can I have my job back" and they go "sorry you can't you're not a proper staff worker, cos it's a good team and you keep getting ill" and this.

Naem [male, 25-29 years, long-term condition]

They were paying me very little money, because they knew that I am retired and I am getting money from the government, the council. So they were giving little money... I couldn't complain because if you are retired and you are only allowed sixteen hours a week. And not more than that. I was working more than that. I was working more than sixteen hours. More, now thirty nine now thirty or less than that. I was feeling quite bad with that but you can't do anything. Either I work there for that money or not.

Zulfikar [male, 70-75 years, family member with own long-term condition]

The Valdas and the Udher ki were particularly reliant on home-work, most often tailoring *shalwar kameez* for other Asian women on a loosely self-employed basis; tailoring wedding outfits for the glamorous Asian clothes shops on Green Street; or doing the “rag trade”, i.e. subcontracted garment work for markets or high street shops on a piece-rate basis. Health problems among machinists were common, and many of the women directly attributed their ill-health to the physical strain of doing close, detailed sewing work under arduous conditions. Home-work allowed employment to be combined with childcare and negotiated alongside normative constraints on women’s employment. However, as Kabeer shows, preferences for home-working are embedded in labour market constraints rather than linked straightforwardly to culture (Kabeer 2000). The reliance on home-work related to the Valdas’ arrival in the UK during a time at which home-work was abundant due to the need for flexible, cheap labour to sustain manufacturing; their poor qualifications and skills, particularly English language; and weaker access to information and contacts about jobs through their women-centred networks. Women’s informal work also blended indeterminately into reciprocal exchanges of services with family and friends – sewing, childcare, preparing samosas and large catering orders for functions, taking in paying guests, managing tenants, applying *mehndi* (henna), make-up, hairdressing and eyebrow threading, and teaching the Quran or Urdu.

For women with long-term ill-health, there could be certain advantages to doing the forms of informal work that were akin to self-employment, such as sewing *shalwar kameez*, rather than piece-work. The relationships with clients were generally personalised and multi-stranded, providing moral space in which to negotiate a flexible workload. Safia wouldn’t take on work unless she felt that she would be able to handle it at that particular time: “whereas a normal person, a normal tailor it would be like a day’s work but it would stress me out and I wouldn’t take on something that I can’t do”. Risham said that “if I’m well then I’ll do it, if I’m not then I don’t, I don’t work every day”. If the tailor were going through a period of sickness, the clients might also allow them to take a little more time over it than usual. However, the informal claims made by family and friends could also be powerful, and it could be equally difficult to refuse work from clients who they encountered in many different contexts.

Piece-work was more difficult to combine with long-term ill-health as the workloads were fixed. Failing to complete the weekly assignment had to be explained to anonymous middle-men who had many women on their books; women whose reliability and punctuality slipped due to ill-health were released promptly from work, with no recourse to employment law.

She'd be still up working on it 4 o'clock in the morning. It used to be that kind of pattern for mum. And she'd have to wake up early about 8 o'clock to get us ready for school. And if she wanted to pay us to go to mosque, she needed to do extra work. She'd fall behind. She'd say that, she'd you know tell the workman who used to come and collect the garments, this was a regular – oh I'm not ready, come back. It was like talking to a brick wall.

Azhar [male, 30-34 years, family member]

The informal nature of *shalwar-kameez* work meant that the impact of ill-health on work could be insidious, with women experiencing a gradual transition in terms of the kind and quantity of work they would do. Negotiating a cessation of work with other family members, who relied upon their supplementary income for domestic consumption and to take the pressure off other earners, could be more significant than negotiations with clients. Billo's husband Shakil, for example, was fine with her giving up piece-work, but only after they had bought a second house, the rents from which "equalled out" her earnings (see Chapter 7).

In addition to those who were reliant on the grey economy as their main source of income, there was also a minority who used the grey economy as a convenient source of supplementary tax-free income. There were resonances with Pahl's claim that the core of the grey economy in the UK consists not of 'welfare scroungers' but of already-employed people who are 'on the make' or 'doing the double', and taking on second, undeclared jobs as part of a strategy of accumulation (Pahl 1990). As Mariam commented rather gleefully, "everybody's got their little bit of *hera pheri* (trickery)" (this is explored further in Chapter 7). Counter-intuitively, being able to command a cash-in-hand job could actually be a sign of a strong bargaining position with an employer, who was sufficiently in need of the employee's assistance to take the risk and create an undocumented position. Informants would say that they would "only do it cash-in-hand": it was up to the employer to sort out how this could be done. Some of the informants engaged in informal work sporadically and opportunistically to supplement their earnings whenever they got into debt (which might be frequently). Shazia took on cash-in-hand work on top of her "English job" whenever a lucrative opportunity presented itself – if her health would permit it; despite her multiple long-term conditions, she was still the primary breadwinner in her family, earning more than her Mangeter husband. On one occasion, a second job helped her to pay for a large plasma screen television, of which she said "it's what I've always wanted". Similarly, Nafisa's husband was a small-time crook who was involved in a variety of "dodgy deals and things like that, he's not quite straight"; "he likes anything dodgy just because it comes cheap or whatever". He once

gifted his family a stolen television, but Nafisa made him get rid of it as she thought that it wasn't right.

6.3. Orientations towards being out of paid work

As the previous discussion suggests, there was a downward spiral between long-term ill-health and unemployment, each reinforcing the other in a cycle that became harder to break out of as time progressed. This section discusses the informants' prospects for (re)gaining employment, in relation to their 'local worlds' of home and community. The long-term sick informants who were out of work had varied orientations towards (re)entering employment. People who were accustomed to being in employment initially found being out of work traumatic. They talked about worklessness as a daily ordeal of boredom, with insufficient routine, purpose and distraction, and too much time spent at home under the feet of their family members. There was a lot of talk about unemployment being a factor that exacerbated ill-health, triggering a decline into greater frailty, disability and premature old age. In the abstract, most of the informants talked about work positively, as a protective factor which allowed them to remain physically, mentally and socially active. However, not all of the informants subscribed to the notion of work as core identity, and there were others who inhabited – or who had managed to carve out – other valued social roles.

6.3.1. Becoming long-term inactive and the life-cycle

For men, whose identities were bound up with the masculine breadwinner ideology, worklessness could initially be extremely emasculating – particularly for the Babas, who had lost jobs as industrial labourers, imbued with connotations of strength, dignity, pride and strong union activity, and as such, a considerable source of working-class masculine status. They talked with pride about their achievements in their previous occupations. They talked a lot about the ethic of self-reliance; that they ought to be able to provide for their families themselves, and that worklessness was a sign of failure. A couple had turned to alcohol after becoming *berozghar* (unemployed). However, despite their professed dislike of unemployment, most of the long-term sick Babas had been out of work for such a long time that they had become reconciled (with varying degrees of adjustment) to the prospect of never being able to find another job. Their inertia was explained in relation to the needs of the wider economy, which they felt had changed so much that they had no skills to offer in the labour market. The way Khaliq saw it, "gone are the days when anybody who can't even speak English can still move some stuff, right, but now

it's all technology". For most of the Babas, employment had receded out of the realms of possibility. Razzaq commented despondently that "before I was trying but I gave up now. I'm 54 years old, you know? I won't get a job".

The role of the "elder", the *barhe*, offered them the possibility to carve out valued social space for themselves, taking on involved roles as parents and grandparents, and immersing themselves in communal domain of mosques, associations and political parties. Family roles could be somewhat problematic for the Babas, as the protracted proximity to wives and female kin could be a little uncomfortable. Norms of sex segregation defined the household broadly as female space, and the Babas could not participate as freely in the casual give and take of sociability and chat that went on in the home when only the women, children and younger males were present. Family members, too, could be resentful that the Babas had been remote from domestic affairs for so long during their working careers. Khaliq complained whimsically of how his family called him the "bad guy", expressing his peripherality in the home.

Well, my children, they're more close to their mum than me. I'm the bad guy [laughs] because I spend too much time outside. That is the... but sometimes I think yes, they are right. I should have given them a bit of time. But that's the price you pay for community work. Not only me, many other people. Your personal life does suffer, your family does suffer. "Your place is in the community centre".

Khaliq [male, 60-64 years, family member with own long-term condition]

In contrast, the community domain offered a more important space for the Babas to build up new, redefined lives for themselves. Sadiq saw communal labour as directly equivalent to paid employment, visibly enjoying the time he spent "working" in the mosque: "there's no time limit in how much time you can spend in the masjid". They defined themselves not through their occupations, but through their positions in the community vis-à-vis their peers and the successes of their children. In the community domain they performed valued roles in creating and maintaining the ethnic infrastructure needed to reproduce a transnational Pakistani community. Their role was to express the 'moral voice' of the community (Etzioni 1995; 1997) and make sure that the Lads and Idher ki internalised the norms and values of Pakistani Muslim society. They were usually more concerned with their children's unemployment, which disrupted the expected and appropriate roles of provisioning and dependency between generations, than with their own.

The Babas were able to draw on cultural ideologies surrounding economic inactivity as a state that was appropriate and even laudable for people in the life-cycle phase of the *barhe* (elder). The Babas' pride in children who had taken over the responsibility for breadwinning reflected the *izzat* (honour) or symbolic capital that accrued to a family if an elder could be seen to stop work as soon as their sons became *jawaan* (grown up) and started earning a living for themselves (see Chapter 7). For the Babas, the capacity to sit back and be supported by a host of loyal children was a visible sign of prosperity, family unity, and of having successfully brought up respectful and respectable offspring. Furthermore, the Babas were able to legitimate their inactivity in relation to the ideology of the 'community of suffering' (Werbner 1980) (see Chapter 5). Early retirement was explained with recourse to the hard work and adversity they had endured in order to build a secure future for their families. Now, they considered that they had done enough; and it was time for the next generation to take over. Indeed, some of the Babas had chosen early retirement *without* even being pushed by long-term ill-health, in pursuit of family and community roles that they valued more than employment at this phase in their lives – although I suggest that this should also be understood in relation to the contraction of the industries in which they had worked. Interestingly, some of the Kakas were also actively planning for early retirement, which was an important part of their aspirations for a successful later life. At 38, Shahid was already looking towards retirement: "after 40 it's your time for relaxing".

My boys started work so then I said fine, I'll leave the job. I worked at the Ford til 1992 – I worked there for 22 years. The payments from the Ford came at the end of the 90s. Those people that wanted to take voluntary retirement got a payment for that. So I thought alright, I'll take early retirement, and I'll pay it back by working for the community instead. So like now when people come to the centre sometimes I drop them home if they haven't got any transport, I get job satisfaction if you like. I suppose I could have got richer if I had worked another way. But all I need is clothes, a roof over my head and roti (bread) two times a day – so what's the point?
Abdul [male, 55-59 years, no health condition]

The availability of the social role of the *barhe* (elder) mitigated the loss of self-esteem that men often suffer during unemployment, and could be seen as a 'cultural resource' that younger men did not necessarily have. However, embracing and taking on the role of the *barhe* was not a straightforward expression of agency: the 'conditions of possibility' for the Babas were constrained by the opportunities presented by the wider economy; their experiences of economic restructuring, recession and, as Beatty and Fothergill have suggested, state policies towards health-related benefits, which hid the true extent of industrial unemployment and encouraged

strategies of incapacity benefit claiming rather than re-engaging with work (Beatty and Fothergill 2004).

Employment was even less of a priority after the onset of long-term ill-health for the Valdas. The Valdas also shared the ‘community of suffering’ narrative and claimed reputations as hard workers. They talked about work as an act of personal sacrifice undertaken to secure a better future for their families. For them, long-term ill-health usually translated into an increased immersion in family roles, particularly with parenting and grandparenting. In contrast with their husbands, the Valdas had invested more in their family ties and domestic life, and tended to enjoy more relaxed and spontaneous emotional closeness with their children than the Babas. Emotional ties underpinned the centrality of the Valdas in the domestic arena, which allowed them to become matriarchs: withdrawal from paid employment did not affect women’s authority as much as for men. They also engaged actively in the inter-household domain of kinship and friendship, partaking in the moral sanctioning of the young and the politics of status maintenance – the formal and informal gift exchanges between families at ceremonies; passing on of information that could establish or injure family reputations; and in their ritual and religious observances (see Papanek 1979). Indeed, in some sections of the community, women were able to draw on class-laden ideologies of *purdah* and claim moral prestige (*izzat*) and symbolic capital for inactivity, which implied that the family had prospered sufficiently that their women were not out to work. In Ayesha’s words, her mother was now enjoying “the good life of sitting at home”; “she was quite happy that she’d stopped working and she was a woman of leisure!”. Inactivity could therefore also be a way of increasing status.

The prospects for employment among the Valdas were further limited by what Pollen describes as ‘premature ageing’ (Pollen 2002). Gulabo acknowledged the relatively youthful nature of Pakistani women’s entry into old age compared with their White counterparts: “after 50 years of age the only thing that matters to you is looking after your health and what matters to you”. However, she was also careful to present it in relation to the wider context of their lives: “their ladies [White women], they have one or two children, they know the language from birth, they have big jobs to do, they send their children to nurseries. Our people on the other hand, we don’t have the capacity to send our children to nurseries and also work”. Interestingly, she recognised that their prospects in the labour market were limited on many fronts: health, qualifications and skills, their weak labour market position, large families and caring responsibilities.

Some of the younger male informants with long-term ill-health had also attempted to create valued non-work roles for themselves, turning towards community and religious activities as the organising principles behind their everyday lives. However, it was difficult to have these activities legitimated in the eyes of the community than for the Babas, as their youth precluded them from being valid inhabitants of inactive roles. As I discussed in Chapter 5, Ubaid and his brother Yasin – who were both incapacitated by long-term ill-health in their 30s – were actively taking on the entire social identity of the *barhe*. Nonetheless, Ubaid’s acquaintances registered “surprise” that he was perennially out of work, as it did not seem appropriate to someone of his generation. His account illustrates the importance of the social process of ageing in the legitimation of inactivity in relation to stage in the life-course.

Although I’m only 36 and my father hasn’t retired as me, he’s like in his 60s he’s always running round doing this doing that, meetings whatever he’s a busy man you know? But even when I speak to some other people – oh, what are you up to? Just at home and that, relaxing and er... they’re a bit surprised, you know? Cos I’m a young man aint I.

Ubaid [male, 35-39 years, long-term condition]

6.3.2. Prioritising looking after the home and caring roles

Orientations towards paid employment among the younger female informants were extremely varied, and differed according to generation and migration histories, the rural or urban background of households prior to migration, the class position of the household in Pakistan as well as in East London, and the women’s educational status. For women who had never engaged in formal employment, or whose last job had been before they got married, long-term ill-health tended to be just one of many factors that combined to keep them out of the labour market. For some women, particularly poorly qualified women with migratory origins in rural, poorer areas of Pakistan, paid employment was not very relevant to their current lives. They derived a sense of being hard-working and productive through their work in other arenas, such as household maintenance, caring and the communal domain. As I showed in Chapter 3, they were often living with large numbers of children and sometimes also with, or very nearby, elder family members for whom they had responsibilities of *khidmat* (care). In many cases, home-making and motherhood brought satisfaction and enjoyment. Motherhood was an important source of status and recognition. However, in some of the rural-origin sections of the community there were also strong normative pressures against female employment, which was taken as a sign of women profiting greedily at the expense of their children’s upbringing. In this normative context, it is not

surprising that many of the female informants espoused women's normative 'traditional' roles. Research shows that inactive Pakistani women consider inactivity to be a sign of status (Ahmad, Modood et al. 2003) and that 80% of Pakistani women who are inactive due to looking after the family do not want to work (Salway 2007a). However, such 'preferences' are to a large extent embedded socio-culturally and economically (Lewis 2006). Conforming to 'traditional' gender roles can be seen as an expression of agency, within the limits to the 'conditions of possibility'; albeit one which involved colluding with patriarchal structures which offered women status in exchange for accepting the status quo of the gendered division of labour.

It is important to note that the 'traditional' gender ideologies cited in relation to economic activity were multifarious and class-bound. The Valdas who migrated from rural Pakistan had generally been involved in a variety of economic activities prior to coming to the UK, particularly activities within the rural subsistence economy such as tending to livestock. As young women, productive work was an important way for them to prove their worth in their marital homes through the work they contributed to the household, and also a matter of feminine pride and honour. Umbreen's mother's rationale for making her work on the machine after her marriage was that "she has to do it, she has to pay her way". Furthermore, the objection of the 'moral voices' was not towards paid employment *per se* but towards public forms of economic activity outside the home, which was associated with poverty and moral looseness. As Mariam said "it's not in terms of money, it's going out. I used to do sewing at home. That's ok but going outside, that's like people in the *biradari* will say bad things". For some of the women, particularly those who were of Mirpuri or rural origin, the seclusion of women from visible employment – or their withdrawal from work once it became affordable – was an important means of signalling high social status.

If you don't need the money I think most people would prefer not to work. They'd just prefer to sit at home... You can live with your pocket money you get from your husband and... lady of leisure!
Safia [female, 25-29 years, long-term condition]

In families with urban migratory origins and higher levels of education, cultural ideologies constructed women's employment as a sign of household modernity, and it was as a valuable source of a second income. For some women there was pressure to work; a moral imperative upon them to better their lives and those of their children. Asif lamented of his sister, who had worked alongside her visual impairment until getting married and having children, that "I think she's wasted sitting at home but you know, at the end of the day that's her choice".

The women who were being pressured to work complained particularly strongly about their difficulties in having their health conditions recognised by their family members, and were at pains to portray their household maintenance and caring roles as sufficient and legitimate work to keep them busy without employment, as well as sufficiently valuable to the family as a whole. Sayeeda, for example, believed that her depression and “the things that I’ve been through” meant that she should not be obliged to do paid work, but was under a great deal of pressure from her parents and siblings who called her *phalto* (useless). She cited the authority of Islam and Pakistani tradition concerning the complementarity of gender roles in the face of pressure from her family members, saying that she should not have to work because “in our culture men do everything, every single thing”; illustrating how powerless individuals could actively draw on ‘officialising strategies’ (Bourdieu 1977) in pursuit of their own interests, including complying with the status quo. Sayeeda argued that she had kept up her end and conformed with her family’s wishes in performing her ‘traditional’ duties as a daughter, daughter-in-law, wife and mother, and that she was entitled to that role; drawing out the interdependence of claims and obligations, power and responsibility.

People say to me why can't you work? Why are you not working? Number one is that I've got no qualifications. They married me off so incredibly, incredibly young and in Pakistan you have a very, very restricted life. I had to do what my in laws wanted me to do. You know, you just do the housework you just have kids and you just do what they say.

Sayeeda [female, 35-39 years, family member with own long-term condition]

The pressure on women to (re)turn to work was also affected by the economic status of the household. For example, Shaheen’s husband’s orientation towards her being out of employment changed after he lost his business and ended up unemployed. As Shaheen described, he saw her as a potential source of dual income and wished for her to earn as well. However, her health condition was such that he had no alternative but to be understanding about her health-related limitations, and he eventually had to agree with her and encourage her not to work. However, his ambivalence towards her working should not detract attention from his authority over her decisions about work; against which she rebelled covertly, applying emotional pressure on him by claiming her status as a sick person (see Chapter 5) and his responsibility to her as a husband.

Since we lost the business, my husband wanted me to work... he never wanted me to work before. And one of the things that if I be honest, that makes him get angry with me is that he always says to me that all your sisters work except you. And then I have a go at him and I say to him, well

when I wasn't working for 20 years you didn't say anything then! And now, just because the business has gone down the pan now you're saying to me to work. And I said well who's going to look after the kids, who's going to do everything? And then sometimes I get really annoyed and I say to him, alright then, well I'll work, I'll work, then. Then he'll go, well you can't work in your condition. So he won't let me work but he still wants to carry on telling me that I'm not working.
Shaheen [female, 45-49 years, long-term condition]

It is important to note that the female informants cited Islam as an 'officialising strategy' (Bourdieu 1977) in multifarious ways. Younger, educated Idher ki often cited modernist, textual interpretations of Islam as legitimate grounds for *entering* paid employment. Zarida's feelings were quite common; she believed that Islam gave women the right to employment and individuated income, but that this was subverted by a patriarchal Pakistani culture:

It's a cultural thing, what I mean by that is in the Pakistani Asian community in particular, but tied in with that is a religious sort of kind of aspect to that as well – because I think it's very difficult to separate culture and religion sometimes, the two are intertwined – although there are clearly defined roles... it's quite explicitly specified in Islam, that you work if you want to work, you're not forced to work, if you want to be supportive of your husband then that's fine but he has absolutely no right over your resources so he can't demand that you pay this or pay that or look after the children, that is solely his responsibility.

Zarida [female, 40-44 years, family member]

Other educated urban-origin female informants described poignant regrets about never having been able to do much paid work. For them, female employment was part of their aspirations and ideas about a successful life-course. Afshan drew on these cultural ideologies when she said: "I wanted to be successful, I wanted to be called a working mother". They regretted not having had the chance to prove themselves and use their intelligence and education. Nafisa regretted: "what was the point of getting all that education if you're not going to do anything with it". Safuna felt ashamed that she had not worked: "I feel that if the women who have come from villages in Pakistan are working then we who are from towns should do something". However, the combined demands of household maintenance, their caring roles, and the limitations brought on by their ill-health made work impossible. On the whole, family members were more understanding about women's reluctance to (re)turn to paid employment than they were about women's inability to fulfil domestic roles. In deciding whether she should try to get a part-time job as a dinner lady, Iram said of her husband "he said I'll get tired and then I won't be able to do anything else, so

what's the point?". Many women decided to prioritise their domestic roles and maintaining their health over the potential gains from paid employment. Amina wanted to teach, and said it was her *shaunk* (pleasure/desire) and ambition. However, she found juggling paid work, domestic work and her health too stressful and left the job, as the following quote illustrates.

When I came back from the school it was very tired for me, and I also needed some rest. It was difficult me to take some rest because I had kids, house, household work, cooking, cleaning, it's too much to do for me. That's make me tired and also affect on my heart as well. I thought it was easy but no, if it's taking too much, that's will be make me sick. That's not good. I don't want to take any risk on my health [laughs]. That's why I left that job.

Amina [female, 35-39 years, long-term condition]

The economic cost of long-term ill-health among women who were already economically inactive was, therefore, one of income-earning opportunities forgone. As Nasreen observed, "if I would have worked then I think it is obvious that we could have spent a better life". Shaheen's husband's complaints catalogue the economic impact of long-term ill-health among women who were primarily looking after the home. Not being able to draw on a second income meant that the household had to struggle more to participate in forms of visible, prestigious consumption which served as public symbols of success and status (see Chapter 7). Dual income families were able to "prosper better".

I still get the abuse from him [husband]. You know, in that way, that "we could have things, well we could have more things if you were working". Or, "it would be quicker to get something if you were working. Cos everything's on me".

Shaheen [female, 45-49 years, long-term condition]

6.3.3. Trying to regain employment

Employment was more of a pressing question for the younger long-term sick people, who tended to be more optimistic about their prospects of going back to work. For the Kakas and the Lads, the breadwinner ideology was an important source of masculine status and a powerful incentive for (re)gaining employment. Some of the younger men were in extreme discomfort and very preoccupied with getting back to work.

I want to work. I've always been a worker. I mean even – I was up 5 o'clock every morning, I would wake the kids up, get ready and go to school, get up, read namaz [prayers], do this, do that, and I'd be shouting at everyone... I'm ready to rise, cos I'm just that way. I've always got to get up early in the morning. I need to get out and do something. You can't imagine what the last months have been like for me. You just can't imagine it... I feel that it's killing me, I feel so down.
Hossein [male, 40-44 years, long-term condition]

Pressure from family members was an important factor that influenced the informants' feelings about (re)gaining employment. Tackey et al report that the familism of Pakistani society created: "a cultural dimension which decreased the likelihood of [people with disabilities] entering, or re-entering the workforce... There was felt to be an expectation that the wider family will support those who are sick or disabled" (Tackey, Casebourne et al. 2006) (p.95). However, such cultural 'constraints' on employment were not evident in the accounts from East London. In some cases, quite strong pressure was applied on long-term sick men to (re)enter employment, depending on the economic status of the family, and whether their financial needs could be comfortably met through other family members' earnings or through health-related benefits. Senior male kin appeared to have the most authority, reminding the younger men of the ideologies about them earning independently and shouldering the responsibility of providing for their families. By contrast, wives did not appear to be able to put pressure on men to return to employment. Ubaid said of his wife's views rather evasively that "she's alright about it". However, this must also be seen in relation to the ideology of the male patriarch, which meant that long-term sick men could make decisions without much consultation with other family members. Whilst some women might have wished to apply pressure on their husbands to return to work, it appears that they were unable to do, and instead exercised their authority in a less overt manner, via complaint and ridicule. Rauf's wife Nafis, for example, insulted him by calling him a *mareez* (patient) and accused him of fussing and malingering. She was evidently desperate for him to get out of the house and out from under her feet, and for some extra income to come into the household; their only son was also unemployed at the time. However, as the following quote illustrates, Rauf denied that Nafis had any involvement in his decision about returning to work.

K: How do the other family members feel about it, are they anxious for you to get back to work?
No not really, not really er... I think it's happened it's happened sort of thing, it's what I want, so but I think probably push it more, probably pushing me that I want, rather than what the rest of it. I think it's what I want, and I'm pushing more, I'm pushing meself, what I want rather than the

rest of them and... it's something that I want to do, you know, so. So the options would be that if you're going to do how many hours, this and that's the thing they would think.

K: So do you discuss these things with your family as well?

No no no, it's all done in there [points to his head].

Rauf [male, 50-54 years, long-term condition]

As I discussed in section 6.3.2., there were generally fewer expectations that women should (re)turn to work after the onset of ill-health. However, there were some circumstances in which long-term sick women would also seek employment. Pressure from the state was an important factor. The Idher ki who had married Pakistani nationals were pushed to work in order for their spouses to qualify for entry clearance to migrate to the UK: a spouse from a country like Pakistan only had the right to enter the UK if the sponsor had been working and off 'public funds' (income-replacing benefits) for at least 6 months. The legislation disproportionately affected Pakistanis, among whom there is a preponderance of transnational close-kin marriages (Shaw 2001). Zubia struggled terribly with her deteriorating mental health, pushing herself to remain in employment so that she could apply for a visa for her husband to join her in London. She managed to survive work for five months but with only a month remaining she left work, unable to continue: "I just wouldn't give up because I just, I know if I leave then I won't be able to get up again... but after five months then I couldn't do it". The restriction of the right to family life to those defined as legitimate citizens in terms of paid employment created havoc in the lives of people with long-term ill-health, separating spouses from one another indefinitely.

The state also entered the decision-making of the Kakas, Lads and Idher ki in relation to the financial benefits of (re)turning to work. For some, the low levels of welfare benefits provided a financial imperative to get into work. Changes in benefits entitlements, as when children reached the age of 16 or left full-time education and their parents ceased to be eligible for child benefit, were critical periods at which the informants were forced to reassess the benefits of work: "obviously when the money stops you have to do something". However, for those whose housing benefit and council tax were paid by the council, in such a high rent area a (re)turn to work would mean a massive hike in living expenses – and poorly paid work would *reduce* income net of housing costs (the 'benefits trap'). A woman's (re)turn to work would potentially also raise the problem of childcare expenses, which – even if the childcare arrangements preferred by the informants were informal and somewhat less expensive than formal childcare – could make the financial returns to work uneconomical.

The informants who were dependent on benefits were understandably cautious about (re)turning to work if it would mean that they would be financially worse off, particularly as they had larger-than-average families to support (see Chapter 3), as well as additional financial commitments to kin in Pakistan. Furthermore, given the temporary and precarious nature of the employment that was available to them, they had concerns that if they were unable to maintain employment they would face an arduous battle in re-claiming the benefits from the council. Zubia was intractably snarled up in the process of trying to re-gain the benefits that she had lost due to returning to a job that she had been unable to maintain due to her mental illness. The uncertainty about her state of health had caused her to hedge her bets about whether she would be able to return to work, and she decided not to her P45 from her second employer: “I told them to keep my P45 just in case I’m better to carry on again”. This created further bureaucratic delays after she finally applied for income support, and at the time of the interview she was surviving on child benefit alone.

You know how much burden I put on my head for five months? I paid the council tax, I paid my rent, I've paid all the bills, it start to hurt inside when I think about it. And I went through all that and what happened, I couldn't do it!

Zubia [female, 45-49 years, long-term condition]

6.4. Experiences of job searching

Among the individuals who sought to return to work, the prospects of finding employment were constrained on multiple fronts. Many of the informants expressed sympathy with employers' need to be competitive and efficient, and thought it understandable that they would be unwilling to employ people with medical complications and impairment. Others complained that employers had discriminatory attitudes towards people with long-term health conditions and towards older workers in general. Even if they had no personal experience of it, the perception of discrimination could deter them from seeking work. However, the health condition was just one factor intersecting with many making it difficult to (re)gain employment.

6.4.1. Qualifications and skills

Overwhelmingly, the informants' qualifications and skills were not competitive, and Pakistani qualifications were largely disregarded by (White) employers. Many of the informants were pessimistic about their prospects of being given “light work”. As Khaliq pointed out, “I’ve not got much education to get an office job”.

My doctor also said that you should work but you should do halka kam [light work]. But I could not find any light work like security work. My health was not good, blood pressure was sometimes up sometimes down so was my sugar. Who can work in this situation?

Anwar [male, 60-64 years, long-term condition, translated from Urdu]

Furthermore, many of the informants seemed to consider only a narrow range of options, relying on the occupations and sectors they were used to. As Yasin said “you stay in what you know”. This was particularly the case for the Babas and the Kakas. There were few examples of men who had successfully engaged in re-training and re-skilling to allow themselves to move into a new occupation after the onset of long-term ill-health, or who were thinking creatively of what they could do alongside their ill-health. Furthermore, their health conditions sometimes made it impossible even to perform “light work”.

When I left the Ford then I try to improve my, they also like somewhere they try to ask me to do some course. But still the course is difficult, and I can't do anything with lifting. Then I decide we said well, put me into English course. And also driving instructor, teach to driving, to teach to other people. So I take the course for two years... but I couldn't do it because English was weak. Its – another thing make me worried, the driving instructor, once you've got, where you're working, you have to long hours to sit down on the seat. But still like that. Now myself if I drive now, from here to 20 mile, my both legs get pains and not circling properly, numbness.

Sadiq [male, 60-64 years, long-term condition]

That said, higher level qualifications did not necessarily give greater access to job opportunities either; some health conditions were incompatible even with “light work”. Even if their ill-health constrained to low-grade work, the informants who had higher qualifications were unwilling to compromise their identities as educated individuals. The inability to do cerebral work, for which they had bettered themselves all their lives, then resulted in immense frustration. Rauf regretted that “after a stroke, that's forgotten. That life has gone now. You did a degree, doesn't really matter”.

6.4.2. Employment support services

The informants generally had dim views of the Jobcentre, whether they had personal experience of it or not. Several of those who were interested in employment support services were barred

from using initiatives due to the ineligibility of their postcode catchment area or the types of benefits that they were receiving, and identified the Jobcentre as a baffling, Kafkaesque bureaucracy. Summons to mandatory job-focussed interviews drew in some of those who were receiving benefits, but produced mistrust and fears of benefits being cut if appointments were missed or eligibility was reassessed: “sometimes I miss out on an appointment and I get very panicky because now they charge you”. In some cases, the marginalisation that the informants expressed towards the Jobcentre was compounded by the identification of the services with mainstream White society (see Chapters 5 and 7). For example, Afshan only came into contact with the employment services because an Asian friend of her brother’s was working for them, which provided a co-ethnic link. Otherwise she would not have approached them; “I’ve been in with my friend and I’ve noticed they don’t help”.

Interestingly, the female informants were more involved in job-focussed activities than the men (as Tackey, Casebourne et al. 2006 also found). It was common for the inactive women to be attending training courses in English language, computing, Asian dress-making, henna application or beauty therapy. Some were also extensively engaged in voluntary work. Although the informants felt positive about these activities and saw them as helpful and generally self-improving, it is important to note that they did not necessarily see them as resulting in employment. They were a welcome break from staying at home, as they offered a reason for getting out of the house and interacting socially with other women. Most of the courses they attended were delivered at Asian community centres, and were accessed through co-ethnic networks and word of mouth: they were not, therefore, identified with the state.

6.4.3. Reliance on informal co-ethnic networks

Information about jobs travelled through extended networks of kinship-come-friendship, which consisted predominantly of other Pakistanis and other Asians. In some cases, the multiplicity of co-ethnic ties provided space to apply moral pressure on employers to create jobs for which long-term sick individuals might not have been able to compete in an open market, calling upon and reproducing reciprocal ties and obligations. Employers said that they would not grant a person a job simply because they were Pakistani; however, the bounded nature of the informants’ networks and the prevalence of personal recommendation meant that connections tended to go that way.

Before my uncle my mum’s brother, he got me a job in [employer’s name]. Then I got rid of that [employer’s name] and then from there I got out, I was in and out of hospitals and then I just left

everything and then I was at home. And I phoned my uncle, my dad's brother, he could find me a job like a... you know washing machine shops? Through the shops he found a job there for me.
Naem [male, 25-29 years, long-term condition]

I used to go, people used to come, there was a [employer's name] behind my house, they used to come round my house and call me, so I went down there. And because I done that job before a long time ago, around three or four years ago, and that there was another one. So I went down there with a few and just tried it myself...I just wanted to test myself, can I last for long. I didn't feel no pain in my chest, I didn't feel no pain there. I was alright again so then I started doing work, so then I got the job.

Faisal [male, 40-44 years, long-term condition]

Co-ethnic networks were, however, an ambivalent resource. The dense web of productive exchanges of information about employment opportunities was simultaneously permeated with avarice and jealousy over jobs. Mariam promised to recommend Farhana for a job, saying “*main hoon na* (I'm there for you)”; “*kal ho na ho*” (tomorrow may never come), retorted Farhana, quoting the names of popular Hindi films to uncomfortable comic effect. Co-ethnic networks privileged access to certain sectors of employment, but simultaneously constrained the range of occupations that were considered within reach, and frequently entailed prejudicial terms of employment. Co-ethnic networks tended to secure access to low-skilled work in small businesses, and precluded access to jobs outside the ethnic economy. Ultimately, therefore, co-ethnic ties served to reproduce labour market disadvantage.

6.5. Conclusions and implications

This chapter examined the fortunes of the long-term ill informants in relation to their structural location in the labour market, and found that the economic impact of long-term ill-health was not universal or unitary. Employment prospects were affected by their migration histories, gender and generation. The migration process incorporated the informants into a segregated labour market. Their occupational segregation, by virtue of their education and skills, the operation of discrimination from (White British) employers, and the resulting reliance on co-ethnic networks had given the informants an economic niche in which their prospects for job retention in the event of long-term ill-health were generally weak. For the Babas and the Valdas, factory jobs offered good terms of job security and protection, but the demand for labour in these industries contracted sharply in the 1970s and 1980s. Self-employment offered a more secure livelihood and potentially also the opportunity to prosper. However, small businesses too were decimated by the

recessions of the 1980s and early 1990s, and only the larger businesses were able to survive long-term in the event of the proprietor becoming long-term sick. For small businesses, long-term ill-health led to the risk of business failure, in which case the proprietor would lose not only income but also any personal assets that had been invested in the enterprise. The Kakas, Lads and Idher ki were positioned more diversely in the labour market, some in secure white-collar occupations; but for many more, casual and temporary jobs offered little guarantee of employment in a flexible and deregulated labour market. Finally, the thriving grey economy of East London provided some opportunities for employment that could be reconciled more flexibly with long-term ill-health, but under conditions that could be quite prejudicial to the employees.

Cultural norms and values, particularly as mediated through gendered family roles and position in the household, were important influences on (re)engagement with paid employment. The Babas, Valdas and the younger women were able to draw on cultural ideologies surrounding appropriate gendered roles which were supportive of inactivity. However, the propensity to draw on such ideologies was embedded in the limited job opportunities that presented themselves in the local labour market, given the qualifications, skills and contacts of the informants, and to the availability of financial support through health-related benefits. Cultural ideologies were also multifarious, and were drawn upon to support individual interests and action, in diverse ways and to diverse ends. Culture served as more than just a constraint on certain people from participating in the labour market. Rather, ideologies were actively constructed by the informants, reproduced or challenged, within the limits set by the patriarchal arrangements of power in their homes and communities.

Whilst the quantitative analyses in Chapter 3 documented the overall disadvantage in the employment of long-term sick Pakistanis vis-à-vis their White British counterparts, the ethnographic material presented here rather emphasizes the differentiation in the informants' employment prospects by migration histories, gender, generation, class, and education and skills. This differentiation had important consequences for the households' ability to 'get by' financially alongside adult long-term ill-health. The following chapter turns to this question and explores the activities that the informants engaged in to cope with the reduction in income engendered by long-term ill-health, and the implications for their capacity to 'get by' and 'make out'.

Chapter 7: Consumption

jittne chador hain, uttne pao pelane chahie

spread out as many blankets as you have – Urdu saying

7.1. Introduction

This chapter examines consumption in households affected by long-term ill-health. Consumption is the process through which income is used to produce the goods and services that maintain the household in the day-to-day and the long-term. As such, it can be seen to mediate between production and reproduction (Carrier 2000). As Chapter 6 demonstrated, for many, long-term ill-health reduced the informants' returns from paid employment, unpinning their livelihoods; they therefore had to turn to a variety of other economic activities in order to maintain a "decent life" (*izzatdar zindegi*) and reproduce their households. The first part of the chapter examines intra-household labour substitution and the other productive activities that the households drew upon outside paid employment. The second section examines what constituted a "decent life": how the informants subjectively experienced the downward trajectory prompted by ill-health, and the living standards they maintained.

In the chapter I draw on the literature on urban post-industrial livelihoods which has documented the coping strategies that households adopt to respond to far-reaching changes in their circumstances. As I discussed in Chapter 1, the potential for household coping strategies is shaped by the markets for land, capital and labour, and the nature, range and style of state intervention and provision (Pahl and Wallace 1985). Coping strategies are also determined by the social networks in which the household is embedded (via familial assistance and mutual aid) (Morris 1988). I use the concept of coping strategies to capture the wide variation in ways of incorporating the household into the economy and social setting (Anderson, Bechhofer et al. 1994) as well as how the internal household division of labour influences the coping strategies that can develop (Roldan 1985).

McCrone draws an important distinction between households that are 'making out' and 'getting by' (McCrone 1994). This captures the sense of trajectory, distinguishing between households that are improving, coping or even declining. To use the words of the informants in East London, 'making out' involved "getting ahead" and taking part in the "rat race" of competition for social status, which took a variety of local forms. As Werbner has shown, households who were

“getting ahead” were able to assert their class and status distinctions via a “symbolic economy of consumption and agonistic exchange” in which “objects take on meaning as signifiers of taste, status and distinction”, bringing out an integral relationship between production, consumption and reproduction: “reproductive rituals... and especially weddings, encapsulate a complex semiotics of consumption and allow scope for profligate displays of wealth destruction” (Werbner 1990a) (p.xv). However, the downward trajectory provoked by long-term ill-health made it difficult for many of the informants to participate in such a symbolic economy. Unusually, this chapter documents the experiences of the class of households who were only “getting by” (*ghuzara karna*) and unable to compete in competition over status. For many, consumption was about managing the struggle to meet everyday needs without appearing to “lag behind”. The distinction between “getting ahead” and “getting by” is therefore useful as it allows us to understand the interconnections between the everyday decisions that the informants made about consumption and standard of living, and their long-term trajectory in terms of status and security. As in previous chapters, the relevance of Pakistani ethnicity to their ability to maintain a “decent life” is examined through a structure-agency dynamic knitting together interacting material and cultural factors.

7.2. Intra-household labour substitution

The potential to offset the loss of wage income by mobilising the labour of other family members was generally limited. The need to provide care for the person with the health condition increased the burden of reproductive work in the household and constrained other family members’ access to the labour market. Compared to households that were experiencing changes in circumstances due to exogenous factors, such as unemployment or redundancy, households affected by long-term ill-health were much less able to maximize the available family labour power. This resonates with the quantitative analysis presented in Chapter 3, which showed that long-term ill-health produced economic polarisation between households as it was associated with a clustering of economic inactivity within households. Furthermore, compared with other ethnic groups, Pakistani households containing adults with long-term ill-health were particularly likely to be completely workless (see Table 3.10., p.77).

The potential for family members to adapt patterns of income-generating work in response to income loss and the costs of long-term ill-health depended on their differential returns from employment, which were in turn shaped by a range of factors: the individual’s qualifications, skills and experience of employment, and the characteristics of the local labour market (see

Chapter 6). Employment was also affected by normative ideologies about appropriate gendered family roles, such as the masculine breadwinner and feminine household maintenance and caring roles. In households where the division of labour by gender and generation was inflexible, adaptations in employment roles were constrained. Intra-household labour substitution was therefore potentiated by an intermeshing of material and cultural factors in the informants' lives, in the context of the local labour market and the state.

As I suggested in Chapter 3, the impact of long-term ill-health on the economic activity of other household members was strongly gendered. Ill-health in men was more likely to result in household worklessness than ill-health in women. This was partly because the burden of reproductive work limited women from being able to substitute for the lost earnings of long-term sick men. As long as the work involved in doing *khidmat* (caring) for long-term sick men had to be combined with caring for children and parents or in-laws, employment was unthinkable for women – caring usually came without any renegotiation of other domestic work, and employment would mean juggling multiple roles amid constraints on time and energy. The extra domestic workload created by male ill-health was particularly onerous when the family was at the expansion phase and the children were still young. However, the obstacle to paid employment did not stop once the children grew up. Parents felt that the work involved in child rearing actually increased when children got to teenage years, especially girls; they needed to be protected from the corrupting influence of “outside society”.

I gave an interview for classroom teaching assistant but I left it because of him [husband]. I can not do two types of work at a time. I felt that if I start working I could have to come home by 4-4.30pm... and I would be so tired that I would not be able to do anything.

Safuna [female, 50-54 years, family member with own long-term condition, Urdu]

The prospect of women taking on the role of principal earner was, furthermore, threatening to the male breadwinner ideology. There was a widespread perception that having a sick husband was one of the few situations in which it was in principle appropriate for women to be at work when men were not, from the perspective of Islam or Pakistani tradition. However, in practice there was a lot of resistance to the idea of women usurping the breadwinner role. As Nasrullah said, “if the man is ill... there can be many problems if he's incapable of doing a job. In that case the duties can be changed over. But it was never the woman's duty to go to work in the Asian society... the dignity of the man lies in what he is working”. This phenomenon is certainly not particular to Pakistani society: numerous studies in Europe and the USA have identified higher levels of

female unemployment among the wives of unemployed men than among those of employed men (see Joshi 1984; Morris 1988). Nonetheless, the informants interpreted gendered norms concerning acceptability of female breadwinning in relation to Islam and Pakistani tradition – evidence of the importance of gender and family practices to the construction and performance of ethnic identity. Some husbands overtly cited the authority of Islam and Pakistani tradition to resist their wives’ overtures about employment, as shown in the following quote. These can be seen as ‘officialising strategies’ (Bourdieu 1977) used to back up men’s gendered power, transforming private interests into publicly avowable and legitimate interests by appealing to the ‘official’ norms of Pakistani Muslim society.

K: Did you ever talk to your mrs about her working?

No. It's not even something I would really entertain... she's um... well she hasn't worked... you know, from our tradition it's not... it is permissible for a woman to go out and work but really the man really should be you know, doing the hard work. Some people might even feel a bit let down if their daughter or their wife has to go out and work to bring in the money.

Ubaid [male, 35-39 years, long-term condition]

Women also experienced normative pressures from the ‘moral voice’ of the community (Etzioni 1995; 1997) to be seen to be appropriately fulfilling their gendered roles and caring for their husbands. Haseena acknowledged that “I do feel that I should be at home”. Risham felt that if she went out to work people would say “what kind of a woman are you, what kind of mother are you, going to work with other men whilst your husband is at home”. In other cases, women themselves resisted taking over the role of the breadwinner out of a desire to protect their husbands’ feelings, illustrating how gendered power was naturalised or ‘euphemised’ (Bourdieu *op.cit.*) and how its practice was structured by a habitus that made male dominance seem legitimate even to women. Evidently, however, the reservations that the female informants expressed towards employment were not only a matter of cultural ideologies concerning gendered family roles. They also reflected the women’s generally limited returns from employment (see section 6.3.2.). The characteristics of the labour market that barred men with health conditions from employment made it correspondingly unlikely that their wives would be able to find work. Furthermore, the low uptake of employment must also be understood in relation to state welfare, which provided a safety net for households affected by long-term ill-health and lessened the extent of *majboori* (economic desperation) as necessary grounds for women to enter paid work.

It is notable that there were a few cases of women whose personal circumstances and abilities allowed them to respond creatively to these constraints, and took on employment to bring up the family income to a level that would support a “decent life” – particularly because their experiences as exceptions prove the rule. Naseem was helped by higher levels of human capital, being highly educated, with experience of work and fluent English, which opened up better-paid sectors of work. After her husband Rasheed fell sick she retrained as a childminder and registered with an agency, which gave her a reliable job that she could do from home whilst simultaneously keeping an eye on Rasheed and carrying out his personal care. However, her account also showed her careful tiptoeing around the potential challenge to her husband’s status as breadwinner. When she took on an evening shift in a bolt factory to supplement the income from childminding, she explained her decision to Rasheed by saying that she had been feeling cooped up and wanted to get out of the house and “mix up” with other women. However, the justifications she gave were face-saving; neither of them wanted to acknowledge that he was not providing for her financially. Khadija’s experiences, on the other hand, illustrate the constraints and limited returns to employment for female breadwinners. After her husband developed schizophrenia and left his job, she took on piece-work from a garments manufacturer, stitched *shalwar kameez* for private clients, and started letting out rooms in their house. Her limited skills and extensive childcare responsibilities precluded her from better paid work, and she endured years of oppressive relationships with shady subcontractors (as discussed in section 6.2.5.).

All three women experienced breadwinning as a pressure and obligation, and not as a source of power within marriage. The arrangements were highly prejudicial to the women, who ended up overexploited, their time and energy stretched to its limits. Their situations were reminiscent of the ‘redundant men and overburdened women’ described in the literature on industrial unemployment (Dicks, Waddington et al. 1998). Whilst the gendered division of wage employment could be renegotiated, the division of domestic labour proved to be less flexible. Few of the long-term sick men picked up much in the way of domestic work, despite the time they spent at home, and this was not generally challenged by their wives (see Chapter 8). Mariam and Khadija both resented having to work, and they drew on the ideology of the male breadwinner to voice their complaint. Mariam criticised that “he’s a man, and he’s depending on a woman! It’s time he pulled his socks up”, therefore illustrating that women could also use ‘officialising strategies’ about gendered roles to draw out the interdependence of claims and obligations, power and responsibility.

He was the breadwinner for the family, he was the one giving money for his parents. Now who would look after them? These were the things I used to think about and I had my parents as well... Who was going to feed them? ... I used to go mad when I used to think about all this. // I used to be strong... The children used to go to school, I used to bring them back and then I used to work on the machine. And I used to do all the work at home as well. My husband was the type who left it all on me.

Khadija [female, 55-59 years, family member with own long-term condition, Urdu]

Ill-health in women did not usually have much effect on their husbands' employment. Employed women were not usually the sole breadwinners, so they could rely on the earnings of the male partner to tide the family over in the event of ill-health; and men seldom undertook caring responsibilities at the expense of employment. The strategy of protecting the male career was seen as natural and obvious, and male employment was supported by other female family members, particularly daughters and the women's natal kin, who took on caring roles instead of the husbands. Women's unpaid caring work freed up the men so that they could continue working; the livelihoods of several nearby and related households therefore became inseparably interconnected. However, where there were no alternative (female) kin to step in and assist, and where circumstances at work permitted, men sometimes took time away from work to provide *khidmat* for their wives. Most commonly this would consist of accompanying them for medical appointments or providing childcare and company. Some men had switched to part-time work, night shifts or taken jobs closer to home in order to reconcile employment more easily with looking after their wives. Indeed, such adaptations could be quite prejudicial to the men too. Liaqat, for example, worked nights so that he could take Nasreen to the hospital during the day or do the shopping for her if she were unable to do it herself. He returned from his shift at 7.30am and caught four to five hours of sleep according to Nasreen's state of health. He was visibly exhausted, seemed depressed, and his own hypertension was volatile.

It's difficult you know. It's not easy, but I have no choice. I have to do, do my responsibilities. That's not easy you know, very very hard. When you know, when you have to work all night and come home, and don't sleep.

Liaqat [male, 55-59 years, family member with own long-term condition]

In the cases where the men did end up leaving employment, it was significant that the wife's health condition had come on when the family was at the stage of expansion and the children were small. Leaving employment was therefore a response to the need for childcare as well as

looking after the wife. Surprisingly, it was not only the men with poor job prospects or a lack of commitment to their careers that left employment; their number included a successful businessman as well as unskilled manual workers. They seemed to share the quality of having particularly strong and intense affective ties with their families. However, it is important to note that their departure from the labour market was also underwritten by their employers' ideas about appropriate family roles and refusal to permit the men to adapt their occupational role in line with the demands of caring. Gendered norms around caring also meant that social services supported the men by providing childcare and financial compensation which would not have been available to women in the same position.

I have pressure from my work you know, my manager from work, they send me threatening letter, this and that, come to work. I say, you see I have a personal problem. My wife is ill... Social services spoke to each other from my department manager and work manager. Then they made a decision and they gave me another two month you know, for they don't believe... They say you just make excuse, you see. So I said alright, if you are not satisfied, give me the without pay leave. I can't come.

Yunus [male, 55-59 years, family member with own long-term condition]

I had to look after him [son] because he was 12 years old. My wife's cancer. So the social security wrote me a letter. They ask me if I look after the boy they will give me the same money. They didn't give me the same money because I was working 12 hours a day there, and they only gave me 8 hours money. But even then I manage it.

Fasal [male, 60-64 years, family member with own long-term condition]

7.3. Income from property and investments

The significance of the loss of wage income was off-set when the household had a diverse set of productive assets. The informants' prior investments in property therefore provided a degree of "security" in the face of long-term ill-health; people with a diverse set of assets were less reliant on the labour of their own bodies, and less vulnerable to the ruinous economic effects of ill-health. They were also less reliant on state welfare – and, indeed, ineligible for entitlements that were means-tested. Evidently, however, people who developed health conditions at a young age or who were already in financial poverty before the onset of ill-health were unlikely to have accumulated sufficient savings to permit them to invest and purchase property. As Sadiq pointed out: "whatever you get, it's hard to live. So how can you really invest in anything?". Access to

property as a resource to buffer the economic consequences of long-term ill-health was therefore differentiated as well as in turn differentiating.

Of the productive assets, rental housing was by far and away the most important. The relatively high levels of owner occupation among Pakistanis – ironically, itself partly the product of discrimination in the rented housing market during the early stages of migration and settlement (Lakey 1997) – gave them a dependable source of non-wage income without much day-to-day involvement on the part of the proprietor. Rental properties represented a form of asset that accumulated value at a steady pace, but could always be liquidated at a later date to release money for family consumption should the need arise. Properties provided flexibility to people with long-term ill-health as they could withdraw more easily from employment if they had income from rent. “Lifestyle-wise”, it made no difference to the family finances when Billo stopped her sewing work after she became sick; they had income from a second house on rent, which “equalled it out”. Similarly, Hossein decided to cash in the two properties he had on rent after his stroke left him wheelchair-bound and incapable of work, and he was planning to live off non means-tested benefits supplemented by his savings.

If I was to sell off and everything, I'd still walk away with more than a million pound in my pocket. Which is not bad... the monthly income [from the rent] is just covering everything that needs to be covered at the moment. Actually my wife and myself we've decided to sell the two houses, and then just not work. Cos I won't need to work, we'll get by with our savings.

Hossein [male, 40-44 years, long-term condition]

Housing portfolios were mobilised creatively in response to long-term ill-health. Properties were shifted between the rental market and domestic use in accordance with personal fortunes and misfortunes. Rents were an important source of non-wage income even for those who only had one property. Putting one or two rooms on rent to tenants – or *upperwale* (upstairs people) – was a common strategy for meeting mortgage repayments and repaying debts. In some households the owners had invested in internal conversions to allow the house to be subdivided harmoniously, to allow lodgers to move in to cover periodic shortfalls in income. Shazia, for example, had separated off a wing of the first floor from domestic usage, creating a sub-household consisting of a bedroom, kitchenette and small bathroom. She had also illegally converted the garden shed into a draughty room that was rented out to a Nigerian couple (and lived in fear that the neighbours might tell the council about it).

Property “back home” took on a renewed significance for households affected by long-term ill-health. In the early years after migrating to the UK, the Babas had remitted much of their earnings to Pakistan to finance the consolidation of property “back home”. *Kotiyan* (mansions), in particular, were the quintessential and indispensable display of successful migration. The *kotiyan* were built with conspicuous ostentation and not generally treated as productive assets; in rural Azad Kashmir the five-storey *kotiyan* lay empty for most of the year. After the onset of long-term ill-health, however, the relationship of dependency between the UK and Pakistan could be reversed, and property “back home” came to provide the economic security that simply being in the UK had guaranteed at an earlier stage. Property in Pakistan could be put on rent to contribute income to households in the UK. Umbreen and her husband, for example, survived ten years of complete worklessness through a combination of income support and the rents from her husband’s ancestral house in Punjab. Asif derived additional income from some land in Rawalpindi which he had converted into a car park. Surprisingly, agricultural land – incomparably more important than housing in most rural livelihoods – did not seem to be a particularly significant productive asset for the informants, perhaps reflecting the way that international labour migration in Azad Kashmir has engendered ‘capital-rich’ development dependent on remittances rather than investment in agriculture (see Ballard 2003). Property in Pakistan was liquidated in response to financial hardship. However, despite the problems involved in keeping control of property at a distance, the informants were very reluctant to sell off property “back home”. It came at the cost of solidifying a shift in transnational identities, and making a commitment to spending the remainder of their lives in the UK. As well as marking out status, *kotiyan* were after all “security”, allowing the possibility of a later return to Pakistan. Umbreen’s mother advised against selling the family *koti* in Punjab: “it’s good to have a place in the village... where would you go if the *goras* (White people) kicked you out, then where would you go”.

Propertied households therefore had access to sources of income aside from paid work and benefits, and took primary responsibility for their own reproduction; releasing the state from its welfare obligations at the cost of depleting their own private assets.

Plate 17: Migrant mansion and surrounding agricultural land in rural Azad Kashmir, 2005. The three-storey *kotis* (mansions) are a quintessential display of successful migration.



Source: author's own.

7.4. Welfare benefits

Kalra says of unemployed Pakistanis that “state support was not the most significant initial source of income” (Kalra 2000) (p.144). However, for the long-term sick Pakistanis in East London welfare benefits were absolutely the primary source of alternative income, provided that the household had not accumulated sufficient wealth to tip it over the threshold for benefits that were means-tested. Patterns of benefits use were complex. Although many of the informants depended on welfare benefits for survival, under-claiming was also prevalent – confirming the quantitative analysis presented in Chapter 3, which showed that long-term sick Pakistanis were less likely to be in receipt of health-related benefits than their White British counterparts. Under-claiming also coincided with a certain degree of manipulation of the welfare system. I suggest that both processes reflect the marginality of the informants in relation to the state. Das and Poole define the margins as “the spaces, forms and practices through which the state is undone and experienced through the illegibility of its own documents, words and practices”, “the places where you find people who are insufficiently socialised into law”, “the unruly subjects” (Das and Poole 2004) (p.10). The concept of marginality therefore helps to capture the local manifestations of the state in everyday life in the form of law and bureaucracy to be submitted to or evaded.

State welfare resources were deeply embedded in the livelihoods and coping strategies of the informants. Even in prosperous households, income-supplementing benefits such as DLA and child benefit were drawn upon as a seamless part of the household income. The long-term sick informants experienced a lot of 'churn' or unsteady movement between health-related benefits, income support and unemployment benefits, an observation that is confirmed by Bacon's quantitative analysis (Bacon 2002). Applications for health-related benefits were turned down; at least seven of the informants had incapacity benefit or DLA revoked after being re-classified as 'fit for work' in a medical examination; and many had their benefits suddenly withdrawn as a result of inexplicable, anonymous bureaucratic decisions. Income from welfare benefits was therefore intermittent, insecure and unreliable. The elaborate machinations to elude fraud and ascertain that claimants were genuinely ill made the process of claiming benefits stressful and frequently unsuccessful. Changes in eligibility rulings and periodic re-assessments of benefits impinged violently on the informants, particularly those who had no alternative source of income.

6.4.1. Concerns about the legitimacy of taking benefits

The informants gave complex and internally contradictory accounts of the morality of taking benefits, expressing ambivalence rather than outright aversion towards dependence on the state. The facility of welfare benefits was valued and appreciated in principle. As transmigrants, the informants had a tendency to compare the welfare state in the UK with Pakistan, where the state had a much more intermittent presence and there was no obvious safety net for people with long-term ill-health. Even for those of the informants who seemed to have a dislike of English people, the existence of welfare benefits was the saving grace of an otherwise corrupt society. Shazia expressed this double-edged sentiment in her apocryphal statement that nobody in the UK was "allowed to go hungry": "English people are the kindest in the world, it says so in the Quran". However, for most of the informants, benefit receipt was on some level identified with symbolic loss. Kulsoom's mother told her that "if you sit and you eat, then your food will taste one way. If you work and you eat, then your food will taste another way". The proverb *apne khoon pisina ki kamai us mein barkat hai* was cited (there is auspiciousness in the money you earn with your own sweat and blood). For the Babas, who arrived in the UK during an period when benefits use among Pakistanis was very low, self-sufficiency and self-reliance were utmost virtues in the construction of masculine breadwinner identities. Zubia's father lived by the principle that "we earn money by our own self, by our own hard work. That's the money we should give you know, feed the family". These attitudes engendered resistance to taking benefits. Safuna and Zubia both

fought with their husbands over claiming income support after they left work, convincing them eventually because of the insurmountable hardship they were facing. As women, the responsibility of managing the budget and making ends meet had fallen upon their shoulders (see section 7.8.).

My husband never took income support. He didn't want to have income support. We live on little, but we didn't ask for income support. He wasn't a believer you know? To take money from the government anyway. So I said to him you know, sometime I said to him look you have to go with the system... I used to be pulling my hair sometimes just over money.

Zubia [female, 40-44 years, long-term condition]

The use of benefits was seen as part of a lifestyle, a mark of being a certain “type of person”, implicitly undeserving, and defined in counterpoint to the deserving people who wanted to work for their living. Mariam saw herself as too educated to claim benefits: “I’m the type of person who works”; “income support is for people who are too poor to work”. Earning a living from one’s own labour was a sign of respectability. The informants were quite preoccupied with the dividing line between undeserving claimants who were “fit for work” and deserving claimants who were “genuinely ill”. People whose benefits were revoked or refused felt as if they had been accused of malingering or scrounging. Ubaid protested that “I’m not a sponger. I’m not relying on them to give me some money and then I can get on with my life. I just need a little bit of money, little bit more income just to pay the bills, that’s it”. Having an application turned down exacerbated the informants’ feelings of illegitimacy around their ill-health and had a negative impact on their self-esteem.

Similarly, some of the informants resisted claiming their entitlements despite being eligible, or held out until the last possible moment, because self-identifying as disabled would have come at such a huge personal cost. Amina, for example, never claimed her DLA because “I don’t want to consider myself a disabled people, that’s why”. Afshan didn’t see depression as an illness worthy of being classed as disability: “I’ve got working hands and working feet – it was just depression and putting myself down”. The uncertainty about the future prognosis of the condition lent a degree of indeterminacy surrounding the informants’ state of health, which also hindered the claiming of benefits. Nasreen, for example, did not appeal against the rejection of her claim for higher rate DLA: “I think that hopefully my condition stabilizes and I never need to”. Huma stopped pursuing her claim for carer’s allowance as she saw caring for her mother as an assumed and natural part of her normative family role: “they must have thought because she’s living with her daughter, her daughter’s going to look after her anyway even if she gets carer’s allowance”;

“I don’t want carer’s allowance cos I’m looking after my mum anyway! I thought leave it then”. She felt vaguely as if people who claimed carer’s allowance were “greedy for the money”. The informants who had a household style that subscribed heavily to the ethic of self-reliance therefore went to resourceful lengths to hold off from taking benefits as long as possible.

People who claimed benefits struggled to get by. Benefits gave a maximum of about £5000 per year to an unemployed or long-term sick person aside from housing costs. Claimants were sometimes forced into “outside” cash-in-hand work to provide supplementary income. Ubaid was putting a bit of money into his brother’s business to “help him out in terms of stock” to bring in some extra income “cos I’m not confident about this incapacity benefit appeal you know” (see also Copasirow and Barbour 2004; Katungi, Neale et al. 2006). The practices of the welfare state were self-contradicting. The level of benefits was set at such a low level that it was often impossible to make a decent living on benefits alone, and the informal economy took the guise of a para-state shadow with respect to welfare.

Attitudes towards deceiving the state were conflicted, contradictory, and affectively ambivalent (see Ortner 1995). On the one hand, the benefits system was blamed for encouraging dependence on the state and creating disincentives for people to “help themselves”. Nasreen complained that benefits claimants “want to keep themselves like that, they do not want to get well”. On the other hand, some of the informants attributed the blame to the folk devil of supposed “fraudy” people who lied about the extent of their impairment and were allegedly awarded benefits in preference to those who were hardworking, honest, declared their income and paid their tax and National Insurance.

If you tell the truth, they [government] don’t want to listen anything... Because I’m working there’s nothing for my children for education you know, they said no because your father is working we don’t give you any support. A man who is unemployed that do the job outside, he gets the money from the government you know, they give 100%.

Liaqat [male, 55-59 years, family member with own long-term condition]

Many of the informants believed that benefits fraud was particularly common in the Pakistani community and that “our own people” were prone to abusing the system (or “eating” benefits, according to the Urdu). Sadiq criticised that “Pakistanis are so crook, especially the people from Mirpur. My own countrymen!”. The narratives were drawing on one of the informants’ internal, introspective self-images of Pakistanis: the incorrigible trait of *chalakee* (craftiness or guile).

Strictly for local ears, this talk had resonances with Dench and colleagues' work on East London Bangladeshis, who are said to refer to an unemployed benefits claimant as *ranir mehman* (a guest of the Queen) (Dench, Gavron et al. 2006). However, Dench and colleagues fail to appreciate two important dynamics. First, they fail to see the continuity of their Bangladeshi informants' discourses with the wider culture of the East End. Studies of White working-class society have frequently documented how illegal transfers of state benefits are justified by a subversive discourse of "extraction" that casts benefit fraudsters as smart, streetwise folk heroes (Pahl 1984; Hobbs 1988). As Pahl points out, in the wider context of a state that has an expressed ideological commitment to enterprise culture and reducing the tax burden, people who practice fraud and evasion "may see themselves somewhat cynically as practising 'self-help'" (Pahl 1990) (p.33).

Second, the rhetoric of "extraction" may also be seen as a creative way of dealing with the humiliation of having to claim, rather than part of a greedy culture of entitlement. Scott considers self-help to be one of the 'weapons of the weak' available to a subordinate group; a form of political agency and everyday resistance to the power of a dominant body (Scott 1985). Interestingly, several of the informants' talk about "extraction" conflated the state with wider White society. Tariq, for example, only worked cash-in-hand because "you've got to keep one step ahead with this *gori hukoomat* (White government)!". The personification of the state as *gora saab* (a colonial term meaning White sahib) allowed the informants to identify their position metonymically with that of Pakistan as an underdog in the British empire. The quantitative findings presented in Chapter 3 are a useful check against the suggestion that benefits fraud was widespread among Pakistanis in the UK: long-term sick Pakistanis were actually much less likely than their White counterparts to be in receipt of health-related benefits. The subversive talk about the *gori hukoomat* did not, therefore, tap onto a widespread practice, but onto a widespread awareness of imperialism and historical injustice and their effects on the contemporary world order.

7.4.2. The incoherence of welfare state practices

In common with other long-term sick people who were eligible for health-related benefits (Salway, Platt et al. 2007), many of the informants failed to claim as a result of low levels of knowledge and awareness of benefits entitlements. The route to health-related benefits was often happenstance, as a result of unexpectedly being passported onto benefits by health professionals or social services. Few of the informants had used the assistance of professional benefits advisors, despite the extensive infrastructure of outreach projects organised around benefits entitlements in

East London. Co-ethnic ties were often the conduit to benefits, illustrating how the informants' claims to formal entitlements depended on informal social ties. Local Pakistani networks seemed to be quite productive informal sources of information and advice around benefits. Fluency with the benefits system was embodied in specific individuals, particularly the Babas, who were invested with know-how and willing to share their knowledge of the ins and outs of the benefits system. Within families specific individuals were called upon habitually to fill out application forms. These individuals had the magic touch in dealing with bureaucracy, and tended to be English-speaking, educated, articulate and competent. In practice, therefore, interactions with state institutions were mediated by the cultural capital embodied in the advocates from whom the claimant had help, illustrating how class advantage (or disadvantage) was reproduced via informal processes of inclusion and exclusion.

The process of claiming benefits was often arduous and required vast reserves of self-efficacy. Chasing up applications or appealing against rejections was more difficult in the presence of financial hardship. The lack of a car, for instance, made it harder to chase down claims, and having to repeatedly ring up and badger officials was an inconceivable burden on a stretched phone bill. The context of financial hardship meant that the returns to pursuing an uncertain claim might be so marginal as to be disregarded. Mehek gave up on her DLA claim for that reason: "there's nothing you can do then. I didn't bother". Amid the demands of managing the health condition itself, the complexity of "things going on in the house" and the fact that many of the informants had little contact with the mainstream institutions of the state, it is remarkable that so many of the informants *did* appeal against benefits rulings. Connections to prominent individuals in the community (particularly the MPs and the Pakistani councillors) were an important supporting factor. Through their networks of family, community and involvement in the labour movement and local politics, the Babas had privileged access to such individuals, and political influence thus diffused through the community through 'weak ties' (Granovetter 1973).

There are two or three advantages of doing things in the mosque. One thing is that there's sawab (religious merit), and then also you get to know everybody... The other day a girl came in with two disabled children and the DSS had stopped her benefits for no reason. She came to the mosque and said uncle please can you help me, you know the MP. I know him very well. So because of that I went to talk with him and he got the benefits put back after a week.

Sadiq [male, 60-64 years, long-term condition]

There were important ways in which the informants were marginalised by the 'illegibility' (Das and Poole 2004) or incoherence of the benefits system. First, the potential for welfare benefits to mitigate the economic stresses brought on by long-term ill-health was limited by the systematic divergence between the realities of Pakistani family life and the normative White ideals that informed the 'benefit unit' construction of the family (Roll 1991). Pakistani families have higher shortfalls of benefits income relative to needs than families from other ethnic groups. This is primarily because the larger than average number of children in Pakistani families leaves them disadvantaged by payments of income support, child benefit and tax credits that do not increase additively for each extra child (Platt 2003c; Bradshaw, Finch et al. 2006). Carer's allowance did not increase with an increased number of cared-for individuals in the benefits unit. Furthermore, a complicated oddity in the rules meant that income support recipients who were living in large or extended families were likely to make a net loss through claiming carer's allowance¹.

Secondly, the potential for welfare benefits to mitigate the economic stresses of long-term ill-health was also constrained by the state's failure to recognize the legacy and intergenerational reproduction of transnationalism. The transnational to-ing and fro-ing of first generation migrants sometimes meant that they lost their entitlements to social security. Residence requirements like the 'habitual residence test' defined eligibility for certain benefits; others were determined by National Insurance contributions. The prevalence of transnational marriage among the Kakas, Lads and the Idher ki meant that there were differential entitlements to state welfare within households. Sayeeda's husband, for instance, had come to the UK for treatment for his terminal cancer, but as he had not worked in the UK he was not entitled to claim benefits. As Sayeeda was unable to take on the breadwinner role herself and support them in the UK, they returned to Pakistan and relieved the state of its obligations.

Transnational marriages were, furthermore, stuck between the conflicting requirements of immigration law and the benefits system. A spouse from a country like Pakistan only had the

¹ Briefly – at the time of fieldwork, if a person on income support claimed carer's allowance (£45.70 a week) they would not profit from the extra benefit, as it would be classed as income and immediately deducted from their income support. Nonetheless, carers who were on income support were still recommended to claim carer's allowance, as it could passport to carer's premium (£25.80). However, if the cared-for person was sufficiently disabled to qualify for the severe disablement premium (£45.50), the interests of the carer and cared-for person would come into conflict. One of the rules for claimants on severe disablement premium is that nobody should be receiving carer's allowance for looking after the claimant. Whilst the carer would benefit from the carer's premium, the cared-for person would therefore lose a net of £20 a week. Even if the cared-for person were entitled to an enhanced disability premium (£11.70), the benefit unit would still make a net loss of £10 a week. Thus, for income support claimants who were living in large or extended families, as was disproportionately the case for Pakistani families, the benefits unit might end up making a loss through claiming carer's allowance.

right to enter the UK if the sponsor could prove that for at least the previous six months, they had adequate income and accommodation to support their overseas spouse without recourse to 'public funds' (i.e. benefits). In the endeavour to prove financial health and protect their husbands' immigration cases, Mariam and Zubia were therefore obliged to give up their entitlements to income support. Zubia's immigration solicitor had also discouraged her from applying for legal aid, and she had been forced to take an enormous loan of £6000 from her father to pay the legal fees for three rounds of appeals over her husband's immigration case. The lengths to which women went to get their husbands to the UK reflected their need for the social security that comes from marriage, even if they risked financial security in doing so. In brief, many of the informants were heavily reliant on state welfare to survive; but the state was not particularly dependable. State practices were incoherent: the state spoke with multiple voices, and made contradictory demands of its citizens.

7.5. The moral economy of kin and community

Commentators have explored the dense web of productive exchanges among Pakistanis and generally stressed their potential to create value and provide economic support. Kalra states that unemployed Pakistanis relied more on a 'communal support system' than on state support: "in the same way that they had relied on each other when they first came to Britain, family members and friends in work provided a short-term financial fall back" (Kalra 2000) (p.144). However, I found that among the long-term sick Pakistanis in East London, informal financial support mainly came into play in meeting short-falls in benefits. Informal transfers served to tide people through the sometimes lengthy periods whilst they were waiting for applications to be processed or reassessed, and provided money to meet needs left unmet by the low levels of state support, in accordance with norms and values surrounding familial support and reciprocity. The responsibility of supporting long-term ill-health was thus placed onto the community itself – and particularly, as I explain, onto women-centred networks.

7.5.1. Regular transfers and gifts

Financial support has been observed to be more extensive in Asian families in the UK than in White British families (Finch 1989; Herbert and Kempson 1996). Indeed, financial transfers from adult children to their parents were part of many people's hopes and expectations about the appropriate flow of resources between generations, and transfers from children were often more acceptable than role reversals between husbands and wives – and more fiscally advantageous,

given the limited earning potential of older women. The informants drew from strong normative frameworks surrounding the hierarchy of kin who were responsible for financial assistance, which were stratified by gender, generation and position in the household structure (see Shaw 2004). The ideal was for sons, particularly elder sons, to take on the role of financial provisioning for their parents and younger, unmarried siblings after they became *jawaan* (grown up). In several cases, the eldest sons had dropped out of education to enter full-time employment and “pick up the financial burden” for the whole household. The Kakas and the older Idher ki sometimes talked about having given their pay packets to their parents at an earlier stage in their lives, or having had their pay packets taken away from them. As well as a degree of pride at having contributed to the financial wellbeing of the family, some of them also felt exploited. Nowadays, however, working adult children retained control over their own pay packets and budgeted separately. Financial support therefore took the form of responsibilities for specific expenditures such as rent, bills or items in the weekly shopping. It also took the form of gifts, which were particularly important in providing long-term sick people with large or unusual expenditures such as consumer goods, home repairs and events like children’s birthdays or festivals such as Eid.

The internal economic connections of the household were flexible. Asif, for example, took over the gas and electricity bills as soon as he started working: “my mum never ever said to me you know, ‘give me your money’, it was a matter of ‘can you get the milk and bread’ and so on, ‘here’s the money’”. The boundaries around flows of production and consumption between generations were therefore blurred. Similar transfers of financial support were provided, less commonly, by siblings and cousins. The Babas also ended up providing financial support to children who were long-term sick. However, in this situation the reversal of the normative direction of financial provisioning between generations was problematic. For instance, Sayeeda’s parents resented the fact that they were effectively paying for her rent, and concluded that she was *phalto* (useless); their resentment was bound up in their unwillingness to see her depression as a genuine illness and legitimate grounds for her not being able to work.

It was all about the fact that the house was just a family house [belonging to her parents] and me and my three kids were in it... Initially my mum and dad were very nice but when they realised that because of all the tension that was going on because of us lot then even they started being not nice! Not in front of me but you realise things, you realise that you’re phalto (useless). Like unwanted, unneeded, of no use.

Sayeeda [female, 35-39 years, family member with own long-term condition]

As Finch and Mason have shown, norms and expectations are interpreted, rather than followed; drawn upon contextually, and depending on circumstances (Finch and Mason 1993).

Consequently, the financial resources that could be accessed through transfers depended on the economic status of the other family members. Athar had been paying his adult son's mortgage since he had fallen sick and had to leave work, but complained that "my income is limited, I got my own living". When children had large financial commitments of their own, they would also cease to provide for their parents. After marriage and the birth of children, the need to provide for ailing parents came into conflict with the need to provide for the conjugal family. Thus, as Vera-Sanso has also argued (Vera-Sanso 1999), inter-generational relations were mediated by the conjugal relationship. Many parents seemed to tacitly accept this and minimise the claims they made on their children's resources. Yusuf reasoned that "you know what children here are like – they do what they can, but they've got their own expenses, their own houses. I don't ask them much on the financial side". Bashir also said that "now they have their own families I don't ask them anyway". Similarly, Zulfikar's son was underemployed due to the fact that his Pakistani Masters degree was not recognised in the UK; Zulfikar had grudgingly exempted him from his normative responsibilities for financial support, but his disappointment with the son's financial arrangements was evident from the following pointed remark.

There are no hope of extra money. My son he's not earning that much money and he's paying more than hundred pounds for that rent for that house and the rest they spend on the conveniences, so actually they are eating with us and we are supporting them.

Zulfikar [male, 70-74 years, family member with own long-term condition]

Financial support between parents and children was a major arena of contestation within families. Children who were experiencing financial hardship felt pressure to shoulder financial responsibilities for their parents, and parents were frequently disappointed. The failure of children to provide financially for their parents was interpreted as part of a pervasive narrative of inter-generational decline: the rise of what Cohen calls 'the bad family and other modern things' (Cohen 1998). Narratives about the superior morality of South Asian culture and society can be read as an inchoate resistance to the domination of the West; a 'weapon of the weak', appealing to superior moral decency compared with dominant groups (Scott 1985). These common sentiments were captured by Imran: "Asian people live for other people... *gore* people just live for themselves". Or Maheen: "our people are doing too much for their sisters and brothers, too much. The English people are not doing".

In the UK context, the dwindling of financial support to parents was attributed to the corrupting influence of English society and culture. The Babas and Valdas often expressed sadness that the younger generation were wrapped up in “their own lives” and had “no time for their parents”. Mazhar accepted a loan of £10 from his son, who then asked for it back: “children of today are in their own selfish worlds!”. Parents complained that they were made to feel like a burden in the UK, and were not the respected benevolent patriarchs that they would supposedly have been in Pakistan. The Babas felt emasculated by their loss of authority over the younger generation, as exemplified by their abandonment of their financial obligations. They also blamed the welfare system, as children’s entitlements to state support had done away with the economic interdependence between parents and children. Nasrullah, for instance, felt that “the environment here is completely wrong, it’s *ulta* (topsy-turvy). The government gives them a house and money, so the children don’t need to respect their parents”.

For parents who were long-term sick, the *act* of asking children for financial help was particularly problematic. Parents were resigned to the fact that the children might evade their requests and continue to fritter their earnings away on their own *fazool kharchee* (frivolous expenditure). Some felt that it was better simply not to ask the children for anything. As Liaqat put it: “thank god you know I don’t expect anything”. Safuna alluded to the shame entailed in asking explicitly for support: “they have their own life. They have their own problems. And it does not even look good”. But *if*, on the other hand, children were to provide support *of their own accord*, and without being asked, it was an extremely auspicious sign of family unity, of having successfully brought up respectful and respectable offspring and inculcated them with Islamic and Pakistani values. The children were said to have turned out well (*bache achhe nikaley*). The following quotes illustrate these contrasting sentiments.

I said to him “would you pay the bills now you’re working”? Well “yeah I will, I will, next time, next time”. He’s on his own little thing ennit, “I wanna buy this I wanna buy that”, every time he gets paid he goes and buys some clothes and... I said let him get on with it, go and buy whatever you want... I don’t want to demand off him, know what I mean? It’s his money isn’t it. So he doesn’t buy anything really for the home or anything like that. I pay for all his food and sometimes he moans, “oh why don’t you get this”? I said “why don’t you buy it then”? But you know I’m tolerant of that.

Ubaid [male, 35-39 years, long-term condition, speaking about his 19 year old son]

Anytime if I need some money he's always here. Sometimes he buys. Last time I bought a telly he paid the money. And the time before, I bought a car, he paid the money. He always helps me. If sometime he get a loan from some companies then he don't want to mention to me. And when he gets a loan I think, well he's just try to help me. Because they are good, he's whatever Islam says, how to respect your parents.

Sadiq [male, 60-54 years, long-term condition, speaking about his eldest son]

Daughters and daughter-in-laws felt less obligated than sons to provide financially if their parents became sick. Gendered normative expectations about the provision of *khidmat* (care) meant that parental ill-health usually had the opposite effect, making it *more* difficult for them to engage in employment. Indeed, the constraint on the younger women's capacity for employment was one of the factors that made *khidmat* such a bone of contention within families. Farhana didn't want her mother's ill-health to "interfere with" her work, and argued that "for me, it's not my duty now, because I feel now that it's my sister-in-law's duty to look after my parents". Her sister-in-law Nagina would have quite liked to go out to work, and felt a bit aggrieved that Farhana was profiting from her own inactivity. However, the capacity of daughter-in-laws to realize any ambition to work was restricted by their relative peripherality in their marital homes and limited labour market prospects (particularly for the Udher ki).

It wouldn't work. My wife has said to me, "oh, let me, let me go and work somewhere" she goes. I goes, "it's entirely up to you at the end of the day". I goes, "mum needs a little bit of support, er... a lot of support at home".

Asif [male, 30-34 years, family member with own long-term condition]

There were also taboos against accepting financial support from daughters according to the 'traditional' normative framework concerning financial support between kin. I heard various explanations for this, relating it to the principle that "a daughter dies to her parents after she is married". According to the logic of patrilocality, a daughter was destined to leave her natal home and enter another family, who were supposed to be entitled to the fruits of her labour. Daughters who continued to support their natal kin were therefore subverting the appropriate use of resources of their husband's family. Similarly, parents who accepted such financial transfers from their daughters were profiting unfairly from their affines. Paradoxically, however, the increasing entry of Idher ki to the labour market meant that unmarried working daughters represented an important economic resource. Living at home without paying rent, daughters actually had the opportunity to make enviable savings and could have greater economic independence than their

parents. Shanila exuded a gentle paternalism towards her mother's financial needs: "I know if my mum's whacked up a great big credit card bill then I kind-of slip her fifty quid and say don't worry about it!".

As I discuss in Chapter 8, saving up to pay for their own weddings was an important way in which daughters' paid employment contributed to the family finances. Unmarried working daughters also presented a valuable source of labour to supplement their parents' welfare benefits. Daughters were seen as more dependable than sons and affective ties with daughters were said to be more spontaneous; daughters were said to help out of love rather than duty. However, some of the parents who relied on their daughters for financial support expressed a sense of shame at resorting to such measures, which were reprovved by the 'moral voice' of the community. Financial support from daughters was therefore concealed to protect the *izzat* (status) of the household.

I don't want any from them [daughters], no way. Yeah, sons can do... but we don't take anything from my daughters. They try to give a little money can help – this help is here, I don't mind – to clean the house, if it's a small thing they want to buy something for their mum, so then I don't mind. But not, not those things.

Sadiq [male, 60-64 years, long-term condition]

I was talking about [working in] Tesco and my mum thought that it was like bestee (dishonour) working in Tesco's, cos they're gonna think that they're so desperate for money they have to send their daughter out to work... I go "people won't think that". She goes "yes they will". Cos everyone lives around here, that's what it was.

Nafisa [female, 30-39 years, long-term condition]

7.5.2. Loans and borrowing

Indebtedness has risen in recent years; it is endemic to post-industrial economic life and associated with stress, anxiety and depression (Parker 1992). The individuals who were in the worst financial circumstances and whose lives were most stressful were those who had taken out large loans from banks and high street credit companies. Yunus perennially moved his debts between different credit cards: "pay on one, take it on to the other, pay on the other, take it on the other one, like this we manage something. Pay to the bill on the credit card, pay the interest, little bit of money you know". Mariam was at her wit's end and owed debts of £9000 on her credit

cards as well as £2000 on an Argos store card; she vowed that “if I can just get through this I’ll pay off all my debts and then I’ll cut all my credit cards into tiny pieces, I’ll never touch them again”. For this reason, many of the informants viewed banks and credit companies as last resort, and a dangerous one at that. Credit cards were seen as having a life of their own, and owning one courted trouble. A minority of informants also raised objections to credit cards and commercial loans on the grounds that they contravened the Quranic prohibition on usury. However, they also felt that they had to accept certain non-Islamic facts of life in the British context (see also Herbert and Kempson 1996). The low use of consumer borrowing was therefore more affected by the fear of credit as a dangerous and self-perpetuating cycle than by the adherence to Islamic precepts. Afshan took it as a point of principle that she wouldn’t become “a credit card holder”. The fecklessness implied by taking loans was contrasted with the ethic of self-reliance of the deserving poor.

I never want to borrow. But I don't borrow to smoke, I don't smoke, my son doesn't smoke. I don't borrow to... if you like for go-karting... We try not to borrow even for food, it's only sometimes because it's gone over.

Mumtaz [female, 50-54 years, long-term condition]

Many of the informants expressed a reluctance to become indebted to agencies beyond their own networks, in keeping with various studies which have found low-income Pakistani families to be more averse to commercial loans than their White British counterparts (Sadiq-Sangster 1991a; 1991b; Herbert and Kempson 1996). However, the gendered use of credit within households was notable. Men were more likely to take commercial credit from institutions such as banks, credit cards or moneylenders, whereas women were more likely to rely on pawnbrokers, friends and relatives, reflecting women’s more restricted individuated ownership of property and assets, access to information and occupational status. Men were also more willing to take on larger loans, particularly those that formed part of a strategy of “getting ahead”, such as mortgages for houses, domestic improvements, cars and consumer durables. Nafisa and Safuna, for instance, argued passionately with their husbands over taking on loans for consumer goods, out of the desire to protect the financial security of their families. Women, who tended to carry the responsibility for domestic budgets and making ends meet, were more likely to take smaller loans for the purposes of everyday “getting by”. During the months when Razzaq was withholding income support from her, Haseena was forced to borrow from “almost every single person like I knew”: “sometimes I need to buy for the kids, I couldn’t. Sometime I turn up to his family or to

my family to borrow money and carry on buying stuff because the money he's getting, he's not spending it, and what I'm going to do?"

In many cases, men were somewhat insulated from the strains of making ends meet on the budgets set by household income. Where the wife was not earning, the commonest pattern of financial management was for men to give their wife a fixed housekeeping allowance that was not only inelastic to everyday contingencies in need but also made it difficult to plan ahead. As Guriya complained, "he never talks to me [about money]... it's hard for me to know as well, what's going in and how much of our expenses are going off, our budget... ok fair enough I'm not that educated I've not worked, but don't make me much more of a pea than I am already, do you know what I mean?". Women were therefore obliged to turn to their own sources of income. Difficulties in meeting expenditures on the housekeeping allowance were one of the commonest reasons women cited for taking on informal paid work. Risham stitched *shalwar-kameez* because she needed "clothes for the kids, clothes for myself, or if there's someone I need to give a gift to, because my husband won't give me anything... it's not like I'm spending it on gold, it's not much money". They also turned to their own sources of credit to meet everyday expenditures, and the burden of reproducing the family was thus shifted onto women-centred networks (see section 7.8. for further discussion).

The amount of money that could be obtained through informal networks, and the frequency with which loans could be taken were inevitably constrained by the financial circumstances of the individuals who constituted those networks. In the same way that there was polarisation between dual-earning and workless households, so were the networks of extended kin and neighbourhoods polarised and interdependent; knitted together by material exchanges and lacking much intimate contact with households whose circumstances differed from their own. Mumtaz, for example, was reluctant to ask for anything from her daughter Afshan, as Afshan was also struggling financially and coping with her mental illness and a difficult pregnancy on her own (her husband was still in Pakistan and waiting for his UK visa).

I don't like to ask my daughter for anything cos if she, her husband was here... Sometime when I come here [daughter's house], you know, there's food but I don't want to always take away things from her children.

Mumtaz [female, 50-54 years, long-term condition]

Negotiating informal loans was problematic because they potentially undermined the moral base on which relationships with kin and community were founded. The chronicity of long-term ill-health and indeterminacy about the future that it entailed also brought particular problems in relation to informal loans. The informants feared that their sources of help would tire of persistently giving without any certainty about the prospect of reciprocation or relief in the long term. Mehek, for example, feared that her sisters were getting fed up of the one-way flow of transfers that they had been giving to maintain her independent living. She felt pressured by her sisters' accusations of malingering and not doing anything to better her life. She was making do without necessities but unable to test them any further by asking for more: "they've stopped giving me now". Many of the informants had a taboo around borrowing money from kin. They feared that they would not be able to pay the loan back, and that the repercussions would be worse if it was within the family. Ubaid was firm that "I wouldn't go down that route... I'd never ask from anyone, none of my family, ever". Ties of friendship and neighbourhood were more readily approached for financial support. As Hart observes, friendship provided a release from the burdens of kinship; exchanges were regulated by "the trust generated by shared experience, mutual knowledge and the affection that comes from having entered a relationship freely, by choice rather than status or obligation" (Hart 1988) (p.185). Trust therefore played a very significant part in mitigating and compensating for the economic consequences of long-term ill-health.

The informants' networks of kinship-come-friendship, however, were not as stable, harmonious and interdependent as they have been presented in the literature on survival networks (see e.g. Stack 1974). The informants' networks were threaded together by material need, and seemed to be a contradictory arena characterised by enmity and jealousy as well as mutual aid. Friendship was interwoven with a pervasive discourse of mistrust (*chalakee* or craftiness) and veiled, critical speculation about the true extent of each others' wealth. Sadiq captured a common sentiment: "some people – once they get something they don't want to know. *Chehra badal jata hai* (their face changes). *Hai!* If they need something, they always coming to you. Once they get something, then...". Safuna echoed that "the people whom I have been good to always attack me from behind... if he [husband] had been healthy then maybe they wouldn't have done that". The informants described disgust and disappointment over friends who made excuses and pretended to be out of pocket in order to avoid giving loans, though really they were "minting it" or "raking it in". Ubaid felt that "you only know your friends when you're in a tight spot and they help you out".

Mistrust and rivalry were engendered by the increasingly differentiated nature of the community. The Babas' accounts showed how the trust that characterised the early days of the migration process – the 'community of suffering' (Werbner 1980) – was facilitated by the stability of the needs of the individuals in the networks, who were all of a similar economic status. However, the nature of community ties had changed alongside the growing prosperity of the community. There was less need for forms of collective financial organising such as the *kameti* (a credit association) (see Werbner 1990a; Shaw 2000). Sadiq believed that "now day by day you know, the children get a good education, they got jobs, they help with their parents – *sab yeh lok ittne ... majboor nay hain*" (people aren't so... desperate these days). Most of the informants had given up on *kametis* as a "useless thing" and said that they were no better than saving on one's own. In the absence of trust, community-level pressure to conform and sanctions against defaulting on payments, *kametis* could not function. Naseem, who ran a *kameti*, was personally liable to put in her own money and prop up the association if anybody defaulted on their stake. She described the *kameti* wearily as "a headache". Mariam had stopped participating in the *kameti* because she had lost faith that her money would be returned to her in the end.

I don't do the kameti no more because it's Shahid's sister [her sister-in-law] that runs it. I don't trust her... I used to be in a circle that she was running, but I gave £80 to this Black woman one time and then I never got none of it back. So I don't have anything to do with kametis. So many people have been tricked!

Mariam [female, 35-39 years, family member with own long-term condition]

7.7. Competitive consumption

As the previous discussion suggested, the informants engaged in a diverse portfolio of coping strategies to compensate for the downward trajectory provoked by long-term ill-health. However, for the majority of the informants, long-term ill-health meant a reduction in income, and had implications for their capacity to maintain a "decent life" (*izzatdar zindegi*). The following section examines in more detail what constituted a "decent life" for the informants. Werbner characterizes Pakistani expenditure patterns as a combination of everyday thrift and occasional ostentatious ritual splurge; as she demonstrates, 'distinction' is defined by participation in a symbolic economy defined by agonistic expenditure (Werbner 1990a). Many of the informants, however, were unable to or had difficulties in competing for social status via consumption. In Bourdieu's terms, they were the victims of 'symbolic violence' wielded by dominant classes: "[there is terrorism] in the peremptory verdicts which, in the name of taste, condemn to ridicule,

indignity, shame, silence men and women who simply fall short, in the eyes of the judges, of the right way of being and doing; it is in the symbolic violence through which the dominant groups endeavour to impose their own life-style" (Bourdieu 1984) (p.511). Townsend's relative concept of poverty as "withdrawal from participation in the customs and activities sanctioned by culture" (Townsend 1979) (p.57) is useful in understanding the informants' loss of self-esteem and face. It highlights the relativity of poverty to local symbols, and the function of consumption patterns as codes of inclusion and exclusion in social groups, from which flow a sense of belonging and fulfilment as well as resources.

The downward trajectory provoked by ill-health was experienced as humiliation, as households were excluded from participation in the normative standards of consumption that marked out acceptable social status according to the 'moral voices' of the community. Several informants described it as a "rat race". Ismail said that "the biggest fallback we've had is trying to play catch up... everyone's like going to a certain level, all our peers, all our cousins, they're all beating us to this level and we're on this little band but we have to climb as well". The informants' meagre consumption marked them out as "lagging behind". As Srinivasan has suggested, the informants interacted with three different status hierarchies (Srinivasan 1995). They competed in relation to Pakistan, with friends and relatives from the home village or city; in East London, with other Pakistanis; in East London, with other communities. Consumption standards prevailing locally were an important point of reference. Ubaid was unsettled when he noticed that "everyone changed their car... there were all these new cars my neighbours having". However, the fact that status was largely defined in relation to other Pakistanis rather than other ethnic communities was clear from the informants' feelings that crowing about ones' possessions was an Asian thing to do.

There's so much pressure on with the Asian people with their families that you know, we've done this much, this is how much sone di churrian (gold bangles) we've got and how many cars we've got and how many bank balance, we've built a house back home, it's just like a rat race. You know? That we've got a house here and we're working and you know. And first of all they said oh you're living in a council place? they look down on you. And that can have a huge affect on your mental state as well. Then you come home and you think oh my god we're poor and we haven't got a house, and it just ... then you start arguing you know, then you start snapping at the children or your husband, why have you done this, why — it's so hard. If only they knew. Because in my life, our life has been completely different from them people....

Umbreen [female, 40-44 years, long-term condition]

For first generation migrants, property in Pakistan was the primary anchor of symbolic status (Werbner 1990a). As a result of having steadily remitted money to kin throughout the 30-40 odd years they had spent in the UK, some of the Babas faced the prospect of long-term ill-health with no savings at all. For Zulfikar, the inability to purchase property in Pakistan loomed larger in the imagination than the everyday reality of living in a council flat in London: “our relatives, everyone is saying that why you haven’t made a house there, why you like this and why you er... you should be having your own house and this and that”. At a later stage in the migration process, consumption in the UK became more important than in Pakistan. Housing was at the centre of the status politics of consumption; the onus on owner-occupation and the relative success of many of the Babas and the Kakas in the property market resulted in intense pressures to get on the property ladder. The size and quality of the housing were important signifiers, as was the interior decoration; laminate flooring, leather sofas and plasma screen televisions were coveted and stylish. Novelty was another consideration. Shaheen, for example, made sure to change the upholstery in her front room every two years to keep it “fresh”. Despite these aspirations, however, many of the informants’ houses were in visibly poorer repair than the surrounding properties in the street, with peeling paintwork, broken windows or wonky front gates.

Aside from the status considerations, the informants’ had a dislike for council housing because it offered an uncertain future with no long-term security. Living in temporary housing particularly restricted the degree to which people wanted to engage with neighbours and the locality as temporary housing tended not to be in Asian areas (see also Bowes, Dar et al. 2002). Temporary housing was associated with an oppressive sense of alienation from the wider social environment and a poverty of local resources.

If my husbands' like, if he was working, then maybe this house it would be my house. Then my kids never had to worry that you know, when they grow up then they just quickly move out. We living here, it's our house but deep down it's council's house. Maybe he could have bought the house, and we wouldn't be worrying about it house. And maybe one day they can make that way. That's what I think, what I feel. I do feel that, because all of my family, all the people I know they have houses and his parents, they have house, their own and they put one house on rent and they bought a new, another house. But my life is not that way. It's opposite, totally different. Everything.

Haseena [female, 35-39 years, family member]

Competitive lifestyle strategies centred significantly around weddings, which were important occasions upon which comparisons of status between families would be drawn. Nafisa, for example, did not attend her cousin's wedding because she had no decent clothing to wear. She sent her three elder children to the wedding with her sister, wearing their Eid clothes which they had only worn once before. Nafisa's sister was unwilling to take them into the wedding hall unless the girls were wearing jewellery, and whisked them to a pound shop beforehand to kit them out in plastic. Even then, the other guests at the wedding dinner remarked on the children's wild appearance. Entertaining guests and visitors at home or *daawat* (invitation) was a similar source of stress. Mumtaz, for example, was reluctant to give *daawat* because she was ashamed of the state of her housing, as illustrated below. Financial hardship might mean that a family were unable to partake in social occasions of this nature, which meant that they would be gradually excluded from the casual give and take of sociability that constituted and reproduced membership and belonging to a *biradari* and to Pakistani society (*maashra*). The inability to participate in the moral economy of kin and community incurred a form of 'social death' (Bourdieu 1966) (p.217).

My house is horrible it's like a haunted house very small rooms. My son's wife didn't want to live with me anyway, they had their own rented place. Very rarely they come to see me but I have no objections, they should be happy and enjoy their life. And actually even my daughter doesn't like my house. She jokes that it's a horrible house, I don't want to come and see you.

Mumtaz [female, 50-54 years, long-term condition]

Reproductive rituals such as weddings, births and circumcisions required *lena-dena* (giving and taking), which is a complex potlatch of competitive reciprocal gift exchange within the *biradari*. *Lena-dena* was prioritised and planned for within the family budget. If finances were tight, short-term loans would be procured from relatives and friends to maintain participation. Rauf, for example, explained that "if some of the Asians are going to go for wedding... you know you've got to give some money, so you've got to take all that *beforehand*, you have to do that rather than last moments 'oh, I'm short £300'". Yunus borrowed £300 from a friend to send to his niece in Pakistan at the occasion of her wedding. *Lena-dena* was a key arena in which women contributed to the economic status of the family by creating symbolic capital through relationships of obligation and indebtedness with other households (see Werbner 1990a; Shaw 2000). For women who were not in paid employment and had little individuated access to income, welfare benefits actually played a very significant role in allowing them to participate independently in *lena-dena*. Many women used their child benefit for *lena-dena*, and Asif and Huma's mothers both spent their DLA on it. The independent income to women deriving from welfare benefits could

therefore be significant in contributing to women's wellbeing and standing in their wider *biradaris*. The prioritisation of *lena-dena* in spite of considerable sums involved reflected the unquestioned, taken-for-granted importance of the social ties that were being maintained; from which flowed a sense of belonging and fulfilment as well as resources, reflecting the extent to which the informants' interests were vested in their *izzat* (honour or status) and informal claims from family and community.

Plate 18: *Lena-dena* in Gujar Khan, 2006. Members of the *biradari* attend the preparations for a wedding at the groom's house. The young man with the notepad is marking down the sums of *lena-dena*.



Source: author's own.

Ritual splurge was justified through the logic of the proverb *jirha nay kharcha oh gwach janda* (what's not spent is just lost). Although competitive consumption might appear to be 'irrational', non-economic behaviour, as Bourdieu explicates, it can be understood as a 'sensible bluff', allowing the accumulation of symbolic power which can later be inter-converted into economic capital through social relations (Bourdieu 1977). Indeed, the imperative to keep up appearances through displays of consumption seemed to be strongest for those who were dancing most precariously around the edges of *majboori* (financial hardship). For the poorest of the informants – who were all lone-parent females – any excursion outside the house was necessarily accompanied with good clothing and gold jewellery. Keeping up appearances and maintaining

local standards of decency were important in keeping open the channels of mutually assistive social ties. However, ultimately the only way to participate in the consumer society was to purchase on credit, and risk long-term financial security.

It's that car he's [husband's] got. The low driver or whatever it's called. It's one of those tractor cars. He just wanted to get it. He wanted an expensive car. And that's what happened... This company was giving him a loan, and as he had the loan he thought he might as well get the car... So half his money goes down there as well.

Nafisa [female, 35-49 years, long-term condition]

The pressures on the informants to invest in conspicuous consumption can be seen to have continuity with wider processes in British society. A wide sociological literature demonstrates that consumption has emerged as a dominant mode of experiencing social hierarchy, *meaning* more to people in giving them a sense of 'ontological security' than their position in the relations of production (Saunders 1987; Burrows and Marsh 1992; Edgell and Hetherington 1996). The informants' particularly extreme preoccupation with consumption also needs to be understood in relation to the material and cultural conditions of their lives in the UK. The famously ostentatious consumption of Punjabi culture has been linked with the reproduction of a hierarchical feudal caste system that requires lavish gifting to maintain relationships of patronage or indebtedness (Werbner 1990b) – 'symbolic violence', to use Bourdieu's terms. Whilst the pioneer migrants enjoyed equality and sharing – the 'community of suffering' (Werbner 1980) – the increasing economic differentiation among Pakistanis in the UK is argued to have invigorated cultural tendencies to competitive consumption as a way of consolidating higher social standing.

However, the informants were not merely adhering to a reconstructed Punjabi culture from Pakistan; they also *responded* to the status politics of consumption in various ways. Some of those who could not afford it withdrew from conspicuous consumption altogether. Haseena's friend gifted her a sofa which she didn't like, but as she said, "if you don't have choice then you can't dismiss it". Many of the informants described undergoing a mental shift in which they adapted to thrift and learnt to ignore the desire to purchase what was not "within the limits". "I never buy things unless I have money" ; "you have to resist sometimes"; "when money is there you tend to be more sophisticated; but now we can just think of painting things, repairing and cleaning".

I'm not doing anything flashy. I make my life simple you know, as much as possible... The other time our own people they come they say oh Mr Ali, what are this, same sofas? I say I don't care, same sofas. I say it's good for me, I'm happy, I don't care... People say look so many years you're in this house you know, you have to move somewhere, your house is getting old. I will not change anything in this house. If you come, come. If you don't come, you don't come. I have no problem you know.

Liaqat [male, 55-59 years, family member with own long-term condition]

The growing salience of Islamic identities and of textual, Quranic interpretations of Islam presented an alternative to the norms around competitive consumption, which could be criticised as “unislamic”. The informants were therefore able to draw from the opposing systems of ‘Islamic honour’, characterised by religiosity and austerity, as well as ‘secular honour’, characterised by consumption (see Bradby 2002; 2006). However, the cost of eschewing secular honour was potentially great. Zuleikha had a simple *nikaah* (Islamic ceremony) in which she wore a *jilbab* (a modest Arab-style gown) rather than Punjabi bridal attire; her cousin Imran said of her wedding “what kind of a *shaadi* (wedding) do you call that?!”. The Babas and Valdas were able to draw more easily from Islamic ideals concerning egalitarianism and immaterialism, as these ideals were intertwined with the ideals of renunciation and withdrawal from worldly affairs that were bound up in the ageing process (see Lamb 2000; 2002). As Sadiq said, “now’s time to think about the *aakhrat* (judgement day)”; “I used to want to have nice shirts too, but it’s not necessary now”.

The younger generation were generally more immersed in the politics of consumption and would often prioritise competitive consumption in their budgets to the extent that they would get into debt to do so. The Babas criticised the young for living too much in the present – “they never think tomorrow” – and identified their voracious material desires as a big financial pressure. However, the Babas also gained vicariously from their children’s consumption; competition for status among the Babas took multiple forms, including the achievements of their children vis-à-vis those of their peers. Bashir’s son bought him a new car because his old one was no longer so prestigious: “my third boy he gave me a Mondeo, a Ford Mondeo because I have a Saab, he said no daddy, have that. He give me the help”. Bashir protested outwardly at the expense, but was visibly pleased with the display of dutiful and respectful provisioning.

Plate 19: Preparing luggage for trip to Pakistan, East London, 2004. Gifts to relatives in Pakistan were an indispensable sign of successful migration. The cost of gifts was prohibitive. Often visits to Pakistan were restricted to older men.



Source: author's own.

7.8. Making ends meet

For many of the households affected by long-term ill-health, consumption decisions were not about “getting ahead” but the matter of “getting by” and maintaining everyday life (*ghuzara karna*). “Getting by” was highly dependent on the domestic work of women. In this respect, the female informants’ domestic roles were similar to those described in the literature on White British families (Brannen and Wilson 1987; Glendinning and Millar 1992; Parker 1993), except that the gender divisions of labour in their households were particularly strict. Budgeting was a very significant part of women’s work, as the way women reconciled financial commitments determined the level of consumption at which the family would be reproduced (see Graham 1992). Haseena, for example, saw her role in the household as “my job is just, save for the children and give it to them what they need now”. Inputs for health, such as food, heating and clothing for children, were prioritised above forms of expenditure deemed to be less essential. However, such expenditures were also elastic, so in circumstances of extreme hardship they would be cut down upon and difficult choices made.

Ideals surrounding nurturing, wifely duties and motherhood meant that most women prioritised food shopping even in financial hardship. It was a point of personal honour for Shazia, for instance, that she never stinted on food: “I’ve always protected these four [her daughters] so I’ve always cooked and made big meals for my children”. As her account implies, the needs of children were usually strongly protected through budgeting. Men’s food preferences and food requirements were also given unquestioned priority. Despite the expense, Ubaid bought a lot of lamb because “I like good food”; Asif ate two chapattis whilst the women in his household ate only one. Mumtaz’s father “would eat food and he would throw the rest of the food away and not give me any food”. Hossein’s was the same; “he would be the first to sit down and eat, and then we would eat whatever was left”. Typically, women’s personal spending was the first class of expenditure to be stinted upon in response to financial hardship. As the main budget-makers, women drew on the household income when it was at its most depleted, and many of the female informants reported few areas of spending that they privileged for themselves. As Zubia put it, “you got so many demands from children, so many demands that you have to sacrifice yourself for everything”.

Increased domestic work by women was also necessary to minimize expenditure. A simple way to stint on food expenditure was to purchase the raw ingredients for food and do more home cooking. Evidently, home cooking was not merely a matter of cutting food costs, and cooking food from “back home” was an important and morally-loaded symbol of cultural belonging and of women fulfilling their appropriate gendered roles (see DeVault 1991; Caplan 1997). The substitution of home cooking for “outside food”, “English food” or “junk” was strongly looked down upon by the ‘moral voices’ of the community. It was seen as unnecessarily wasteful, and evidence of poor household management and domestic skills on behalf of women. Cooking Pakistani food had advantages for low-income households. Dowler, for example, has shown that low-income ethnic minority families tend to have a better diet than their White counterparts because of cooking pulses and fresh meat and vegetables (Dowler and Turner 2001). However, evidently, the trade-off was that cooking food from “back home” was more labour-intensive. Women’s domestic work was also used to cut clothing costs, as when women sewed *shalwar kameez* for themselves and their children instead of taking them to a tailor (saving approximately £15). The unpaid domestic work of women thus substituted for, and supported, the low levels of income guaranteed by employers and the state. These strategies were evidently threatened when it was the women in the household who were long-term sick; their health conditions impacted on their capacity to carry out domestic work (see Chapter 8).

In the poorest households, the only way to reduce costs any further was simply to go without. Nafisa and her five children subsisted largely on a diet of rice and *dal* (pulses), pasta with a sauce made of Tesco value tinned tomatoes and onion, and the occasional supplement of eggs. Mumtaz made do on tea, potatoes and bread, often skipped lunch and breakfast and was very preoccupied with her son's weight loss. After her application for incapacity benefit and DLA were both refused, she subsisted mainly through informal charity: "there came a time when like the *biradari* people, they used to send me food and things, they became very worried for me". In such circumstances, material support from kin became even more deeply embedded into budgeting strategies, providing essential health resources on a regular basis, as when the members of one household would habitually eat with another; flexible household boundaries then allowed two households, as defined by co-residence, to merge for the purposes of consumption.

The decisions and actions that women made typically prejudiced themselves in favour of other household members, and expressed and consolidated their weaker position in the household. Furthermore, the 'traditional' balance of gendered power in marriage was reinforced by the benefits system, which perpetuated male authority with respect to financial management (see Lewis and Bennett 2003). For many benefits, the welfare system granted income to a (presumed male) breadwinner and assumed that resources would be pooled between spouses/partners, which inevitably facilitated male control over income. Haseena's husband Razzaq had been keeping the income support for his own personal spending; it took her two years of negotiating with the benefits office before she was given income support separately. She did not blame Razzaq, as she attributed his behaviour to the effects of his schizophrenia, but she blamed social security for their obdurate failure to recognize that she was the person in charge of household finances. As she explained, "I took all the document like doctors letter, she made a note please can you pay her because Mr Khan's not giving any money to her and can you pay her separate money so she can live easy... A long time they write me six months later, sorry we can't pay you separately because your husband is claiming on benefit and then we have to pay and he has to give it to you".

In certain regards, however, long-term ill-health in men did actually *strengthen* the power of women in marriage. Where the husband was profoundly incapacitated by the health condition, the wives ended up taking on a wider role in financial management following the onset of the ill-health, in accordance with their personal circumstances and abilities; and there were also indications that financial management brought with it increased strategic control and broader shifts in gendered power in marriage. For Hossein's wife, for example, control over domestic

finance had also brought increased leverage in other household economic and domestic decisions, and strengthened her authority in other domains: what Hossein referred to as his wife's growing "confidence" – although as he explained, "she's becoming confident now because she has to. She doesn't have any choice now". The withdrawal of their husbands after the onset of long-term ill-health had released untapped managerial potential in the women and brought about a transformation in gendered power. However, the newfound egalitarianism in the marriage was regarded with reservations. Haseena, as illustrated in the following quote, was ambivalent towards the arrangement, and envied other women who had more normal marriages.

All A to Z I have to do it... It's me who makes decisions because he is just never there for which school they [the children] go to, what they gonna do. He was just never there. And he just let me do it... I do feel strong. I do feel that the way I think, what I been doing, I know what I'm doing. I do feel strong. I never feel like weakness that I can't do it, I can't do it on my own... I feel like free. Free, he can't just say to me that don't do that, don't do this. I think that way it's a good relationship, me and him.

Haseena [female, 35-39 years, family member]

Plate 20: Looking towards central London from the top of Ferrier Point, Canning Town, 2006. The economic polarisation of Newham is illustrated by the juxtaposition of the prosperous City of London and Millennium Dome with the sprawling council estates and ex-industrial wastelands.



Source: London Borough of Newham 2007 Calendar.

7.9. Conclusions and implications

The chapter examined the fortunes of the long-term sick informants in relation to their capacity to maintain a “decent life” (*izzatdar zindegi*). The informants’ standard of living generally deteriorated. The household livelihoods shifted from the formal wage economy towards informal work, and further towards the communal and household economies (see Gershuny and Miles 1985). The coping strategies used by the informants were structured as well as structuring; contingent on the resources to which they had access, and on cultural ideologies concerning how those resources ought to be deployed.

Most of the informants upheld a “decent life” through a combination of their own assets, state benefits, informal activities and informal social networks. The differentiation in the employment prospects of the informants, noted in Chapter 6, was associated with differential access to resources, which amplified the extent of economic polarisation between households. For those who were resource poor, long-term ill-health prompted a spiralling downward trajectory. The living standards of women deteriorated particularly, as gendered ideologies surrounding differential roles and entitlements meant that they were frequently over-exploited and bore the brunt of sacrifice in maintaining the level of consumption at which the household reproduced itself. Furthermore, the sharp gender division of household labour made it particularly unlikely that long-term sick people would be able to benefit from the employment of other household members, particularly women.

The difficulties with retaining or (re)gaining employment made many of the informants very reliant on state welfare. The coincidence of dependence, under-claiming and manipulation of the state were characteristic, if paradoxical expressions of the informants’ marginality – in Tsing’s words, “marginals stand outside the state by tying themselves to it; they constitute the state locally by fleeing from it” (Tsing 1993) (p.26). The inadequacy of welfare provision shifted the burden of reproducing the households from the state onto the moral economy of kin and community, supported by cultural ideologies surrounding familial support and mutual aid. However, contestations around financial support meant that informal claims were also changing and insecure. Moreover, the income that could be claimed through informal networks was inevitably constrained by the economic location of these networks.

The informants had their own criteria for evaluating the living standards they maintained: the critical issue was not only the question of whether they were able to “get by” and survive on the

day-to-day, but also whether they were in some way able to “get ahead” and strive towards long-term status, which meant being able to participate in a symbolic economy defined by the fulfilment of locally, socially-defined norms of consumption. The prioritisation of competitive consumption was a way of compensating and concealing the harsh material reality of low income, and therefore can be seen as a form of ‘cultural resistance’ to the downward trajectory provoked by ill-health.

This chapter demonstrated how the regimes of consumption in the households determined the standard of living at which households could reproduce themselves. Like Chapter 6, it also brought out the interdependence between the household’s productive and reproductive activities. The following chapter develops these themes further, and examines the implications of long-term ill-health for the reproduction of the household, both in the day-to-day and long-term, across generations.

Chapter 8: Reproduction

main hasste hasste chaldaa haan

with a smile on my face I keep going – Punjabi saying

8.1. Introduction

This chapter examines the impact of long-term ill-health on the ‘reproductive’ work involved in the household’s everyday and intergenerational maintenance, which is linked to ‘productive’ work in complex ways. I trace the impact of long-term ill-health throughout the domestic lifecycle, from the marriage of the long-term sick individual to biological reproduction, caring, everyday household maintenance, child-rearing, the education of children, and finally to the marriages of the children.

Reproductive work, as defined by Moore, involves: “a great deal more than giving birth to children. It also involves all the activities – cooking, cleaning, childcare, looking after the old and the sick, running the household, etc. – which we usually refer to as domestic work” (Moore 1988) (p.52). Long-term ill-health raises problems for the everyday reproduction of the household firstly by creating new reproductive tasks, as when an individual is socially defined to require care from other people; and secondly by compromising the ability of the sick individual (and those who are caring) to fulfil their expected domestic roles. Long-term ill-health can also raise problems for the intergenerational reproduction of the household. As I discussed in Chapter 1, the juggling of multiple roles by ‘young carers’ has been shown to lead to poorer developmental outcomes in the next generation, indicated, for example, by children’s educational successes, bullying, being unable to take part in leisure and social activities, and maturing before their time (Howard 2001; The Education Network 2005). However, this chapter argues that there is a need to view the impact of long-term ill-health on household reproduction in a more integrated and holistic way.

Analytically, the chapter draws from the concept of status-production work. As Papanek has pointed out, household reproductive work is linked with material production via the multifaceted phenomenon of status. Giving children “status appropriate language, behaviour, appearance, physical and intellectual skills, health, hygiene and self-presentation” (Papanek 1979) (p.777) is instrumental in shaping children’s future education, occupations and marriage alliances, and particularly in societies where parents rely on their children’s support in old age, has implications for the parents’ future economic prospects. Reproductive work therefore generates family status

in ways that can mirror or embellish class status as set out by the household's position in the structure of production. In this chapter I use the concept of status-production work to understand how, in constraining reproduction, long-term ill-health can impact on the long-term status and security of the household, and how the everyday reproductive work of the household feeds into its strategic capacity to 'make out' (McCrone 1994). As in previous chapters, the relevance of the informants' Pakistani ethnicity is considered in terms of social practice, knitting together material and cultural factors.

8.2. Finding a marriage partner

Although not all of the informants had 'arranged marriages', the majority had marriages that were either arranged by parents or negotiated with the blessings of parents (see Shaw 2000; 2001). Long-term ill-health introduced quite specific insecurities and uncertainties into the dynamics of arranged marriage. The most significant was the negative impact of stigma on an individual's marriage prospects. Prospective *rishtas* (marriage partners) had reservations about marrying somebody who might require extensive care or die young and leave them a widow(er), and there was also a broader stigma of association (see Chapter 5). Where ill-health detracted from a person's marriage prospects, there was pressure on families to disguise or conceal the health condition. For example, though Omar's diabetes was so bad that in his mid 20s he was already injecting insulin and had lost most of his hair, his Pakistani wife of six months standing knew nothing about his condition. He had worn a *topi* (cap) during the prenuptial meetings and after the wedding injected the insulin in secrecy, without his wife knowing anything about it. Similarly, Haseena discovered that her husband Razzaq had some kind of illness when she inadvertently found a box of medication in the wardrobe whilst cleaning: "in my family nobody knew. I find out when I was eight months pregnant. I was in the back and there was a lot of injections there. What's it for?"

In transnational marriages the informants ran the risk that families in Pakistan might consider marrying a son or daughter to a long-term sick person in the UK primarily as a means to immigration and then "walk away" after obtaining their citizenship (see Harriss and Shaw 2006). Another salient concern was the possibility that a sick person might be maltreated by their in-laws after the health condition was discovered. Umbreen's mother pressured her to conceal her obsessive-compulsive "habits" in front of her in-laws so that they would not find out about her mental illness – she was perpetually washing her hands and retracing her footsteps. Nonetheless, when the "habits" were noticed the in-laws started an overt conflict with Umbreen's mother over

the deception, saying that “you’ve given us a *paagal’s rishta* (you’ve connected us to a mad person!), you didn’t tell us that your girl had this”. Similarly, Fazila’s in-laws made her leave her marital home and return to her parents’ house on the grounds that they had been duped into taking on a daughter-in-law whose *ulad* (offspring) would be at risk of diabetes: “they say that if we had told them [about the diabetes] then they wouldn’t have allowed us to get married. He’s their only son and he’s making good money and they don’t want him to be married to someone who is ill”. Interestingly, Fazila herself saw the diabetes as an excuse for her in-laws to pick a fight with her. Her husband’s sister (*nand*) had tuberculosis, but nobody had ever complained about that, so she felt that picking on her diabetes was a pretext for other conflicts.

The families of people with long-term ill-health often engaged in a degree of bartering to find an appropriate match. Overwhelmingly long-term ill-health was perceived to weigh negatively against an individual’s marital prospects, in the same way as other negative attributes such as undesirable physical appearance, being poor, uneducated, having lots of unmarried girls in the family or being divorced or widowed. Tasneem, for example, hailed from a “poor family” and initially the only *rishta* her parents could find for her was from a disabled man; the *mangni* (engagement) was later broken after he was upstaged by Anwar, who was a divorcee. The extent of the stigma associated with long-term ill-health was therefore relative to other characteristics that conveyed status. As I suggested in Chapter 5, the extent of stigma recognised was somewhat pragmatic, and depended on the strength of existing relationships and the interests that other actors had in maintaining strong ties with the family. The health condition could be overlooked, or equally, it could be used as grounds for exclusion.

To mitigate the difficulties in securing marriage alliances the informants deployed the kinship resources at their disposal. Charsley argues that consanguineous marriage is a strategy to reduce the vulnerability of the newlyweds as it ensures trust, liability and consent between the two families (Charsley 2003; 2006). Ties with close kin were indeed an important resource in facilitating the marriages of people who might otherwise be judged as undesirable partners. *Rishtedar* (relatives) were less choosy than *ghair* (outside) people and could be counted upon to give a show of solidarity. An ironic Punjabi proverb was cited in the context of marriage alliances – *ghar de bao bhooke marde, toon bahr sadka gwande da* (the people at home are dying of hunger, and you’re out giving alms to the neighbours!) – as a reminder of the ethic of meeting the needs of one’s immediate relatives before attending to those of outsiders. The bonds of fictive kinship could also be mobilised to maintain the security that comes from the “closeness” of consanguineous marriage. For example, Asif’s family was affected by a hereditary, deteriorating

eye disease, and Asif's mother was obliged to turn down the *rishtas* from Asif's cousins in Pakistan on the grounds of medical advice against consanguineous marriage. Instead, Asif's mother asked for a *rishta* with Misbah, who was the daughter of Asif's father's best friend. Asif's father had expressed his interest in Misbah before his premature death; "my dad he'd always said to my father-in-law that you know, 'one day watch, I'm gonna take your daughters over to England with me. Because they're like my daughters'". Asif approached the delicate *rishta* with care, and discussed his health condition openly with Misbah before making any decision. The closeness of the ties between their fathers and Misbah's prior knowledge of the health condition created the trust needed to ensure a viable marriage – the "knowledge", "understanding" and "acceptance" that Asif felt were required.

Misbah knew because my dad would obviously talk about us all the time, and she'd seen my dad... she'd got him his cups of tea and she'd put his dinner in front of him, she'd you know like if he'd spill anything she'd clean it up and so on. So I think she knew what she was getting herself into, and I was very upfront and honest when I spoke to her, I said that when you come into our family it's not something that you're gonna, you know like, you can walk away from, in the sense that you know like with my dad you know you done it because you were asked to do it or whatever, but with me it's going to be different, you're going to be a part of this family and now there's going to be a level of expectation and so on. And you know, she accepted that.

Asif [male, 30-34 years, family member with own long-term condition]

Ostensibly, trust in marriage alliances came from the equality or similarity that held between kin and close friends, and from the extensive and multiplex moral obligations that bound them. However, various writers have argued convincingly that the language of trust actually conceals relations of power (Sayer 2001; Harriss 2003). The insight of trust as a mask for relations of power has considerable purchase over understanding the informants' marriage arrangements. As in Asif's case, the mutual consensus implied by the talk about "understanding" and "knowing" about ill-health lay behind relations of power based on imbalances of status between two families. The informants' status as transnationals constituted a status resource to which other families sought to access, in a process that placed Pakistani nationals at the low-status end of what Pessar and Mahler call 'gendered geographies of power' (Pessar and Mahler 2003). Many of the long-term sick informants married Pakistani nationals rather than British-born Pakistanis, as Hussain and colleagues also found in their study of young Asian disabled people (Hussain, Atkin et al. 2002; Hussain 2005). The desire to settle in the UK could motivate men and women from Pakistan to marry in the UK even if it meant stepping into roles that entailed looking after

spouses with profound long-term ill-health, as in the case of mental illness or physical disability (see also Harriss and Shaw 2006).

Plate 21: Advertisement for a migration agency in rural Azad Kashmir, 2005. The flourishing of agencies assisting aspirant international migrants are one of the more explicit signs of the pervasive migration culture in the sending areas, where international migration is perceived as a more secure investment than agriculture or business in Pakistan and immensely prestigious.



Source: author's own.

Pakistani female nationals, the *Udher ki*, were particularly vulnerable when marrying into families affected by long-term ill-health. Their weak position as a daughter-in-law was compounded by their weak position in immigration law, which threatened them with deportation if the marriage failed within a two-year period (Wilson 2006). Omar, who had been concealing his diabetes from his wife for six months of marriage, described his wife as a *bechari Pakistani larki* (poor Pakistani girl) and admitted that she had “nowhere else to go”: “she was thinking *bechari* (poor thing) ‘*main England ja rahi hoon*’ (I’m going to England), she didn’t know what was in store”. After Haseena found out about Razzaq’s schizophrenia, she felt exploited and resentful that her in-laws had arranged his marriage as a solution to their need for care: “I did feel that he was like, ill person and he need to be looked after, taking medication on time and god knows what else is going to be in future and that’s why they just find someone, get married, then just let him on their way. Then now it’s me to look after him”. Her parents were so “disappointed” with what they saw as Razzaq’s parents’ duplicity that they urged her to divorce him, and promised to stand by her if she did. However, she felt unable do so as she feared it would jeopardize her family name, and she stayed in the marriage. She consoled herself with the knowledge that Razzaq’s parents felt guilty about the matter and respected her. She saw her

marriage as a test of her *sabar* (steadfastness) and drew solace from the closeness to God that she derived from having lived up to perceived Islamic ideals and not having left the marriage: “Islam doesn’t allow that you just leave some ill person that cannot understand why. That’s why I just keeping pushing till now” (see Chapter 5 for an extended discussion of *sabar*).

It was hard to accept it, but I did accept it. Just because of my family, because I always have brother and sister and I believe if like I done something, if I walked out, people would say things in so many ways and then maybe it felt to [i.e. would have affected] the rest of my family. Then just step by step I learned how to live. I had to.

Haseena [female, 35-39 years, family member]

More surprisingly, the transnational power dynamic meant that there were also examples of Pakistani-national men who had knowingly entered marriages that involved substantial caring roles, taking on aspects of domestic labour that would otherwise be viewed as effeminate and transgressive of normative gender roles (see Charsley 2005; Harriss and Shaw 2006). Zubia, for example, was “clinged on” to her third husband, who was still in the process of seeking asylum in the UK. Unlike her two ex-husbands, who had paid little attention to her sickness and “got fed up” and divorced her when she failed to recover, the third husband was a “nice and gentle person”, “very caring”, who helped a lot with the household work and cared for her when she was sick. Zubia acknowledged openly that his fears about his immigration status in the UK made him unusually dependent on her, and that this gave her security in the marriage despite her mental illness. Her reflections on the relationship are strong evidence for viewing the marriage alliances of long-term sick individuals as mediated by relations of trust which actually masked ‘gendered geographies of power’.

He’s a nice person...If I can’t cook, if I’m sick, things like that you know, he’s helping me around. So with him I’m just clinged on. It’s better to be with someone on asylum from back home because at least they don’t leave you. They need you.

Zubia [female, 45-49 years, long-term condition]

8.3. Forming intimate relationships and having children

The onset of long-term ill-health at an early age could have a dramatic impact on the biological reproduction of the family. Although in most cases marriages arranged by parents and senior kin were stable and fulfilling, several informants with early-onset mental illness found ‘arranged

marriage' difficult and had trouble developing a sexual relationship with their spouse. Asif's brother Idrees was not really ready to get married when Asif and his mother decided that it would be appropriate, and Asif had to quite actively encourage Idrees' sexual relationship: "he didn't know the bird from the bees so you know I mean I had to give him very specific instructions, lets put it that way, and you know what I mean it's something that I felt a little bit uncomfortable with but it's something I knew I had to do otherwise nothing would happen [laughs]". Sexual difficulties for the couple sometimes became a problem for wider kin, who were anxious to see the marriage consummated. Umbreen held off sexual intercourse for more than a year, wearing jeans in bed or tying the cord of her shalwar so tightly at night that it bit into her stomach. Her husband did not force her, but he was thoroughly insecure, miserable and humiliated by the harassment from his in-laws about the non-consummation of the marriage. Finally he complained to Umbreen that there was "no point" and that he would rather return to Pakistan and give up his life in the UK than remain in such a mutually unsatisfactory marriage. She conceded, and began to loosen her trousercord. She seemed not to enjoy sexual intercourse but submitted herself to it in order to conceive: "we used to sleep separate but I just wanted to get that done, to fall pregnant".

I never knew the deep hole that I was gonna fall into. The serious bit is the night bit, I never knew that. I thought, well I'm just marrying, it's just a piece of paper that I'm signing. And my life is gonna be the same, I'm still gonna go to work and come back, sleep in my own bed, he's just gonna be living there. But I think it affects you more where my mum used to take me to the cellar, I used to get hit by her, take me in the park, giving me huge lectures that why aren't you consuming the marriage [sic], why aren't you this, and if you don't I'll disown you, this and that.
Umbreen [female, 40-44 years, long-term condition]

Where the marital relationship was very compromised by the mental illness there could be severely detrimental implications for both parties. Naem was a young man with mental illness whose marriage was arranged by his uncle without his full acquiescence. In part, Naem's uncle seemed to have believed that the marriage would help Naem to "get his head together" and solve his mental health problems, but instead the marriage exacerbated many of them. Naem was unable to hold down a job for the required six months to "call over" his wife (see Chapters 6 and 7), which resulted in stormy conflict with various relatives in the UK and Pakistan about his inability to work. Naem and his sisters had to regularly change their landline and mobile numbers to avoid getting harassed by irate relatives in Pakistan calling to complain about Naem having "no brains to work". Whilst Naem was no doubt suffering and unable to cope with the marriage,

the situation was equally bad for his wife, who was running the risk of becoming an 'immigration widow' (Wilson 2006) unable to join her husband in the UK. Her grandparents were taking the failed marriage out on her because Naem could not get a job and bring her to the UK, and she had been beaten several times. For a spouse from Pakistan, often under pressure from their families to get to the UK, the consequences could be more serious than for the British spouse; and young women were particularly in need of the social security that comes from marriage.

Long-term ill-health could also threaten marital intimacy in long-standing relationships, producing difficulties with managing anger and frustration, feelings of inadequacy and lowered self-worth, guilt and shame surrounding the body, and sexual problems raised by the symptoms. The informants often expressed feelings of insecurity about their marriages. Divorce as a consequence of ill-health was, however, virtually unheard of. This partly reflected the enduring love and loyalty that the informants felt towards their partners – many even said that the ill-health had brought them closer together. It also reflected the partners' interests in maintaining the relationships, particularly the women, whose personal status and access to resources were largely mediated through men. A number of the informants also experienced an undercurrent of social pressure to maintain the solidarity of the family and overtly show devotion. Yunus felt that English men would not offer such faithfulness to a sick wife, and would take a lover instead – "if you are English, then I mean they do not worry, if the wife is suffering they just make it friendly". However, he also believed that there were more constraints on divorce for Pakistani people than for their White counterparts, from the mosque, wider family and networks of kinship-come-friendship. Khadija attempted to leave her husband, but her sisters-in-law took her to the park and pressed her to return: "why don't you go back, why don't you go back". Gendered normative pressures to observe 'strong family values' and maintain the integrity of the family therefore became important in the performance of ethnic identity and belonging to a moral community.

For those who had not yet completed building their families, difficulties in conceiving could be the most significant and preoccupying way in which long-term ill-health impacted upon their lives. Certain kinds of health conditions had a negative impact on fecundity and produced difficulties in conceiving. In other cases, the stress resulting from one person's health condition was identified as the source of difficulties in conceiving. Safia, for example, had been unsuccessfully trying to get pregnant for four years before she was diagnosed with polycystic ovary syndrome, which interacted with her diabetes. She was under considerable pressure from her husband and in-laws to produce a second child; infertility was usually blamed on women even when there was reason to suspect that the problem lay with the man (see Bhatti, Fikree et al.

1999; Iqbal and Simpson 2006). Safia said that the disappointment meant that she could no longer be “bothered” with trying to control her diabetes: “you think oh if that’s not going to happen for me then I don’t give a toss about this”. Failure to conceive was particularly problematic for women in the early stages of their marriages. In many cases, women’s position in the marital household remained precarious until they produced children, through which they gained in importance and became ‘central’ (White 1992) to the household, particularly through having sons. Guriya’s narrative illustrates the priority given to sons over daughters: “when they [her daughters] were born it was just ohh it’s a girl, it’s a girl again. It’s just a big letdown... She’s had another girl, waste of time. You know, if our son had married someone else, maybe she would have bored him boys [sic]”.

Plate 22: Sign pinned on door celebrating the birth of a son, East Ham, 2003. Although daughters were more felt to be more loyal and loving than sons, sons were commonly preferred over daughters.



Source: author’s own.

Other couples had decided to put an end to childbearing in response to long-term ill-health as they found parenting so problematic. They doubted the legitimacy of bringing other children into the world, and felt that their adequacy as parents was being questioned. Zubia, for example, had started taking hormonal injections to control her anaemia and gynaecological condition, as well as to prevent herself from getting pregnant again.

I don't want no children. Because of my health I just want to look after me. Me is my children now. Because I know my kids aren't gonna look after me. No-one will. And it's only me and my husband. I don't mind having children but it's very difficult for me to have babies. Very difficult. I have three children and I went through hell with having them you know?

Zubia [female, 45-49 years, long-term condition]

8.4. Needing direct care (*khidmat*)

Long-term ill-health produced additional everyday reproductive work through the need to care for the individual with the health condition. The work of looking after long-term sick people was called *khidmat* (literally 'service'). *Khidmat* was a very multi-layered term which encompassed the additional work of caring as well as doing non-special or mundane domestic work on behalf of the sick individual. However, the additional work entailed by personal care (giving medication, feeding, bathing, taking to the toilet, taking medical appointments, massaging) and emotional care ("being there for", "keeping an eye on") was seen as distinct and of a different nature.

She [co-resident mother-in-law] does quite a lot of things for herself. I'm not her carer I just sort of like do the washing but apart from that she does everything else, she does it herself. So I wouldn't even say I'm like carer cos sometimes she'll even do the cooking and I won't do it... A carer's more like someone who will have to help someone properly like with getting dressed, having a bath, stuff like that. She does all that herself so she's really good and stuff... It's just with household work.

Safia [female, 25-29 years, long-term condition]

Khidmat was an expected part of the responsibilities and emotional work that followed from an individual's position in the household, and was structured by gender and generation. Similar observations have been made in English society, where the norms surrounding care for dependent adults invoke hierarchies of kin (Qureishi and Simons 1987). However, the hallmark of English kinship is individualism and choice, in which the honouring of normative obligations is negotiated substantially in relation to affective ties (Finch and Mason 1993). The informants, by contrast, invoked specific and inflexible normative expectations about the appropriate hierarchies of kin who should provide *khidmat* to people with long-term ill-health. Doing *khidmat* for sick family members was regarded as *farz* (religious duty) as well as a defining cultural practice from Pakistan. The idea that doing *khidmat* might be considered a burden was ostensibly offensive to many of the informants, who said that this was an English notion and alien to Pakistani society. The performance of *khidmat* in accordance with normative expectations was a sign of the

household being *sharif* (decent), emulating upper-class religious identities in Pakistan, and a very important way in which the status of the household was bound up in the behaviour of its women.

8.4.1. Caring between spouses

On the whole, the female informants extended their caring and household maintenance roles to provide care for their husbands in quite a taken-for-granted manner – although this was by no means uncontested. Providing appropriate care for a sick husband was a natural gesture of love and devotion but also a source of moral status. It differentiated households by respectability and was subject to moral comment by the community. As Nadra said “my son’s saying lets go on holiday and get rid of this depression. But I can’t leave my husband ill alone”; “English people, even after someone dies they go on holiday. If we did that people would talk”. However, caring for sick husbands had to be juggled around women’s other multiple domestic roles. Sayeeda regretted that “how much time can you give? I had millions of other things to do, I had young kids and everything”. Many of the female informants acknowledged that caring for their husbands’ health conditions had put strains on their marriage, but saw this as part of their lot and a test of their *sabar* (steadfastness), saying like Safuna that “sometimes I marvel at my tolerating power” (see Chapter 5).

In comparison, there were few examples of men taking on substantial amounts of caring work, and the experiences of the men who did illustrated the normative pressures pitted against them in doing so. Men who did care work were ascribed with subordinate or effeminate masculinities and were often looked upon askance. Umbreen’s husband Najam did a lot for her when she was ill, but this did not appear to be valued by the wider family; her own parents said that Najam was “too soft on her” and raised concerns that Umbreen was being “too controlling with him”. Men who did a lot of care work for their wives were sometimes reproved as *zanmureed* (followers of women) or *bibi ka ghulam* (servant of the wife), or it might be said that *us ne churriyan painhee hain* (he wears the bangles), *goute ke niche hai* or *niche dabbaya hai* (he’s under the thumb). The transgression of expected gender roles ostensibly lowered the status of the household in the eyes of the community. Mariam chided that “even if a woman is in pain then her sisters or her mum should come and help her, it’s a sign of respect if you don’t let your husband do anything for you”.

The doctor told my husband to look after me. My blood pressure was very high but still he made me work. He helped me then only. People said to him ‘toon aurat ke piche par gaye’ (you’re

underneath your wife)... My mother-in-law saw him making me tea and doing the ironing and she used to tell him off. In those three months she really disrespected me (us ne mujhe bahut zaleel kiya).

Risham [female, 35-39 years, long-term condition, translated from Urdu]

There was, however, also evidence of men negotiating with their normative gender roles. As noted in Chapter 6, Islam was used as an ‘officialising strategy’ (Bourdieu 1977) to legitimate both the upholding and transgression of ‘traditional’ gender roles. Yusuf, for example, did much of the personal care for his wheelchair-bound wife, and met the opposition and outright mockery from his children by citing it as his religious duty as a husband. Yusuf had strived to create a valued identity for himself as his wife’s principal caregiver and was fully immersed in the role of carer – he claimed moral status from the sentiment that “no husband will look after her as I have done”.

I do not feel ashamed. I am not proud and not making claims but it is my duty and my religion... I used to go to hospital and give her a shower. Tears used to come from her eyes. I used to push her on the wheelchair. Then she used to feel guilty. “I feel ashamed because you are my husband”. “Marriage is respect for the husband, and you are having to do this for me. Wife is supposed to look after you, you pushing”. But I said “no no no, it is our religious duty”, I used to tell her like this, “if the same thing happened to me would you leave me”. She says “no”. I say “when I don’t feel this, don’t worry about anyone else, no-one says anything, it is all in your mind”. Sometimes the children laugh at me, I used to massage her. I said “I am her partner”.

Yunus [male, 55-59 years, family member with own long-term condition]

The involvement of most of the husbands in personal care was limited. It was noticeable, for example, that Yusuf did not take on the work of taking his wife to the toilet or of bathing her. Rather, these were done by their daughter or by a close female Pakistani friend who lived on their street. The observation resonates with Ungerson’s discussion of the resistance of male carers to personal care not as a norm, but as a taboo, conveying the sense that transgression is polluting and dangerous (Ungerson 1983). However, husbands sometimes took on extensive roles in providing more conventional forms of *khidmat* to long-term sick wives. Typically they accompanied wives to medical appointments; sometimes requiring substantial rearrangements of their time (see Chapter 7). Accompaniment was not only a matter of transport and translation, but was also influenced by gendered ideas about the appropriateness of female mobility in public spaces and interacting with “outside” (*ghair*) men.

Most of the female informants felt that their husbands supported them emotionally as they were going through their ill-health, although they also expressed the idea that men (like children) were not as capable of providing emotional strength as women. In some cases, men's emotional support was constrained specifically by the tension in their loyalties between their natal and conjugal families. Guriya, for example, felt that her in-laws prevented their sons from developing close relationships with their wives because they wanted to secure their sons' loyalty. She complained that her in-laws were constantly pulling her husband back to them, and this was another factor contributing to his failure to empathize with her depression: "if you said [does he care], I'd say, caring for me because I'm the mother of his child, caring for me financial-wise... just the mental, the talking, understanding what's going on in my mind, the whole situation in the house. He just didn't want to". Some of the female informants challenged their husbands' lack of involvement, although the effectiveness of the challenge depended on the quality of the relationship and the wider constraints that the husband was grappling with. Furthermore, some women did not ask their husbands for *khidmat* out of self-reliance and a show of silent strength.

He just gets really short-tempered and he says things which afterwards he doesn't mean, cos it's like yesterday when I came back from the [community] centre I was really tired, I was so tired – and I got caught in the rain as well, and he phoned me and he said are you, are you ok, are you really not well, you know. And he got really concerned. But then you know, he does that when he knows, but he can't help himself [from being short-tempered]. And it's because he can't cope. None of them can.

Shaheen [female, 45-49 years, long-term condition]

8.4.2. Caring between generations

The resistance to men transgressing gendered roles meant that if a wife was in need of care the responsibility generally fell to the next generation instead. *Khidmat* was a normative part of relations between parents and adult children. Parents seemed to teach children from a young age that the devotion children received from their parents should be paid back through *khidmat* in times of sickness or in later life. Shazia cooed to her ten year old daughter: "you aren't going to leave me are you, you're going to help me when I'm old – you're going to be a doctor or something, really successful". Some parents were explicit in deploying the ideology of life-course reciprocity to directly claim care (see also Vatuk 1995), and drew upon the reciprocity entailed by future provisioning in the form of inheritance. Some of the long-term sick mothers also used their

ill-health strategically as a way of securing care through guilt (see Chapter 5), by making explicit their feelings that children's negligence, selfishness and independence was causing or exacerbating their symptoms. It seemed to be quite an effective strategy; children rarely protested against it as emotional blackmail.

I'd never think that way. I think what my mum has done for me or my nan I just... I wouldn't think that way at all, never. There's times where you do feel like oh I'm tired, I can't do this, I don't want to stay [at grandmother's house], I just want my own bed and my own room! I want to go to sleep now. There are times when I feel like that but otherwise not... you know, I wouldn't say that my mum's health or my nan's health is a burden on me. I'd do anything for them in that sense to make them better.

Shanila [female, 20-24 years, family member]

In practice, however, there was a wide gap between the ideals of *khidmat* and the realization of the situation. Many of the long-term sick parents were insecure about their likelihood of receiving *khidmat* from adult children given the corrupting influence of English society and the contingency of *khidmat* to circumstance. The informants also varied in their perceptions of the desirability of joint family living, as opposed to living independently. The feelings of long-term sick parents about asking their British-raised children for help were therefore nuanced and contradictory.

8.4.2.1. Sons

Living with adult sons was a major resource in the provision of care, particularly as married adult sons were a conduit to practical care through daughters-in-law. Living with adult sons also had a symbolic and moral significance that went beyond the level of additional support and care that was provided. Many of the informants idealised the practice of co-residence with sons as part of the nostalgic memory about family values and a defining cultural practice from "back home". The effect of long-term ill-health was to delay the household lifecycle so that adult children would remain with their parents at a time when they might otherwise seek to move out and set up an independent home. In other cases, unmarried adult children returned home to look after a long-term sick parent, particularly in the immediate aftermath of a health crisis. Indeed, this was the phase at which sons were most involved in the practical care of long-term sick parents – particularly the youngest sons, who were the last to leave the "main house" and thus often the ones who ended up living with the parents. Similarly, another consequence of long-term ill-health

was that families consolidated local kinship by buying and moving into local houses – including moving back into the Asian enclave if they had been living outside, thus consolidating the enclave itself and countering the flow of expansive outward movement associated with social mobility.

I personally can't move too far away. There's only one or two reasons. Obviously, who else is gonna support mum. I might have to live nearby. And to be honest with you, that's what I'm trying to do. I am trying to find a place, well, if I can find it, but financially – you know what speed, kind of thing, it's not possible at the moment.

Ismail [male, 35-39 years, family member]

However, it is important to recognize that not all the parents desired to live with their adult sons. Ashraf visited his sons whenever there was a celebration in the family but otherwise “I've got my independence you see, I like to live independent”. Shaheen's mother refused to move to her son's house: “she goes I would lose my independence and I don't want that... Everybody needs their own personal space and in a way she feels like if she's got her house, she's got her own space”. The informants were, therefore, also drawing upon their financial resources (including welfare entitlements such as housing benefit) to challenge the ideals surrounding joint family living.

8.4.2.2. Daughters and daughters-in-law

Some younger women certainly enjoyed good relationships with their in-laws. Indeed, many of the informants believed that the advantage of consanguineous marriage was that the daughter-in-law was already related to her mother-in-law, which was supposed to engender a loving bond between them and protect against the mistreatment of the daughter-in-law. However, the overwhelming feeling was that doing *khidmat* for long-term sick in-laws was servile and exploitative. For many women, the key route to securing a favourable level of *khidmat* was the strength of the relationship they developed with their husbands, who might then be moved to advocate on their wives' behalf and negotiate release from their duties. Nasreen, for example, cared for her asthmatic and diabetic father-in-law for 15 years of her marriage despite herself suffering from glaucoma and diabetes. She complained that her father-in-law had been highly inflexible regarding the amount of work and time she spent caring for him, and resented that her husband had done nothing to stop her father-in-law from making unreasonable demands on her – partly because he was too weak to argue with his father and partly because he needed her to work:

When my father-in-law was there then I used to cook chapattis for him even in my bad health condition [starts crying]. He did not believe me. [My husband] also knows about this... He could not say anything to his father. The chapatti used to be half baked sometimes and sometimes it used to burn. Then my father-in-law used to complain saying that I have not made good ones [starts crying]. He could have eaten bread at this time but he didn't... He [husband] thought that I am doing things and would be able to somehow do it. If I would have folded my hands and would have refused to work then that might have been good. Then my husband would have thought for an alternative.

Nasreen [female, 45-49 years, long-term condition, translated from Urdu]

The level of *khidmat* done by a daughter-in-law was also negotiated in relation to paid employment. The income-earning role of daughters-in-law was sometimes prioritised over responsibilities for *khidmat*, and in this sense income-earning did raise their bargaining power in relation to doing domestic work. Guriya believed that this was a factor that had encouraged her mother-in-law to arrange her youngest son's marriage with a woman from Pakistan. Her youngest sister-in-law was considered to have more traditional Islamic family values and provide more devoted care to her in-laws: "she knows much more about Islam... not that we don't know much about Islam, but it's that Pakistani education is based on Islam and family values. Here it's about what, getting a career, independency, stuff like that... My mother-in-law realised, when we left her she was alone. And that's when she ran and got a girl from Pakistan". Jamila's daughter-in-law, for example, was scarcely involved in care work despite Jamila's quite severe back pain and osteoporosis and her husband's knee operation which had left him unable to walk for three months. Their son was a pharmacist and the daughter-in-law was a solicitor. Jamila called them "busy people"; "the girls with the high flying jobs they come home and say 'mum what's for dinner', they expect it from us!". However, paid work did not necessarily reduce the domestic responsibilities of a woman towards her in-laws – it might merely result in 'role overload' and the juggling of multiple roles.

The provision of care to long-term sick parents had an emergent matrilateral bias. The women who migrated to join their husbands in the 1970s and 80s came to the UK after leaving their mother-in-laws behind in Pakistan. Subsequently, the *Idher ki* largely married male relatives from Pakistan who also came to the UK without their own parents (see Shaw 2001). This has facilitated the flourishing of matrilateral kinship; women maintained denser and closer ties with their own natal kin than usual in the context of Pakistani kinship. By preference, the *Idher ki* cared more for their own parents rather than their in-laws. Networks of female kin and inclusive

household boundaries allowed fluid transfers of care between households, and changed the emotional experience of caring for elders. Instead of the stereotypically conflictual relationship of power and exploitation that characterises the *khidmat* done by a daughter-in-law for her in-laws, the *khidmat* done by a daughter for her parents was given more freely and more lovingly (*piaarse*). For example, Shaheen felt strongly that she and her sisters provided better care for their mother than her sister-in-law: “she can’t feel the same thing as we feel for our mum, because it’s her mother-in-law, it’s not her mother”. Shaheen and her sisters had divided up the week so that their mother could spend different days with each of them and never be on her own. The receipt of care from a daughter had positive emotional qualities for long-term sick parents, who often spoke very warmly about the time that their adult daughters spent with them. To borrow Safuna’s heartfelt words: “my daughter... she is my first friend. She is my daughter, my sister... everything”.

However, the provision of care among matrilaterally-related kin was not devoid of competition and acrimony. The daughter who did the *khidmat* for long-term sick parents effectively became a ‘metacarers’ who herself lost out financially through her exclusion from paid employment, but conversely, permitted her sisters to enter paid employment with *greater* ease. Interestingly, in some of the urban-origin Punjabi households the metacarers’ husbands and parents were actually putting pressure on them to work, and comparing their economic status negatively with that of others in their *biradari*. Shaheen’s husband complained that “all your sisters work except you”, and Sayeeda’s parents expected her to “get a life” like her sisters: “all three of my sisters are very highly studied, they’ve got good jobs, they’ve got their own houses and everything so that’s why my parents thought that she can do the same”. Their *khidmat* had great economic significance: they played a strategic role in freeing up a host of related households to enter the dual income economy, and their performance of religious duty and moral obligation was status-producing work. However, in their upwardly-mobile families this was not valued as highly as income generation.

In their accounts, the metacarers tried vehemently to legitimate their non-participation in employment and convey the economic value of their domestic work to their households. Huma’s mother compared her unfavourably with her sister, who was doing a course in psychotherapy as well as looking after her children and working, and said disparagingly that Huma had “a luxury life”. Huma was at pains to stress that she was too busy to work as she was occupied by looking after her mentally ill mother as well as her two young sons and running her household. Indeed, Huma’s sister was able to work partly because Huma had released her from her caring

responsibilities. Huma and her mother were both competing for the legitimate principal caregiver role. Huma's mother wanted Huma to leave the boys to her and go out to work, but Huma felt that her mother was not capable of looking after them – and also wanted to bring up her sons on her own. Painfully, Huma was feeling undermined by her mother's presence: "by the time we've compromised who's going to do it mum wins at the end!". Similarly, Sayeeda felt that she had been somewhat exploited by her sisters. Whilst Sayeeda had looked after three family members from Pakistan who had come to the UK with terminal stage cancer, as well as their parents, her sisters "just come and they just eat and they leave it and they just go. And I get angry over that cause they don't help". The economic value of the metacarer role was therefore invisible.

Finally, the corollary of the strong mother-daughter bond was that husbands could feel undermined by their wives' dense interdependence and sociability with their own family – resonating with Young and Willmott's observations of the figure of the long-suffering husband, henpecked by his wife and mother-in-law, in 1950s working-class East London (Young and Willmott 1957). For example, Nadir's discomfort with his wife Shazia's role in caring for her parents reveals how his lack of authority in the marriage related to Shazia's extensive family life with her own parents rather than with her in-laws. They had the greater right to *khidmat* according to Pakistani tradition and due to their poorer health, and he had misgivings about the situation.

In our culture a woman shouldn't even see her brothers and sisters and her parents after marriage. In our culture we say that after the daughter gets married we don't even drink a glass of water from her any more. Not because we don't like her or something, but because if a man goes round his sister's house all the time then his brother-in-law's gonna get angry. So you don't see your daughters or your sisters that much because you don't want her to have any trouble off her in-laws... I don't mind, I'm a liberal person but you know what our society is like, people talk, people say things and sometimes you've got to listen to it. She sees her parents too much even though I'm from the paternal side and my dad is older than her dad anyway.

Nadir [male, 40-44years, family member]

8.4.3. Care from social services

The assumption that Asian people have an ethic of “looking after their own” that causes them to rely less on state support than their White counterparts has been criticised as an invalid stereotype that negatively affects access and the delivery of home help and care services to British Asians (Atkins and Rollings 1996; Katbamna, Ahmad et al. 2004; Atkin 2006). It is indeed important to draw attention to the tensions and contradictions in the practice of family care among British Asians, and to how such stereotypes shift the cost of reproducing the family off the state and give rise to a high unmet need for home help and care services. However, “looking after ones’ own” was also an aspired norm for the informants themselves, and associated with very strong moral discourses which had a force of their own. As Murtuja has demonstrated, *khidmat* is a performance of Pakistani identity and participation in the norms and values of a moral community (Murtuja 2005). The ethic of looking after ones’ own and the fear of community disapproval did in some cases lead to an overt rejection of state care. For instance, the 15 years that Nasreen spent looking after her father-in-law were a matter of personal pride. She took solace from having rejected “social help” and from her self-reliance. She gained in personal standing as a *sabarwali* (see Chapter 5) and her entire family benefited from the moral status that came having looked after one’s own and met the normative expectations about household roles. However, such status-production work was usually underwritten by unpaid and unrecompensed female labour.

I looked after him throughout his stay with us. I had never taken any sort of social help. Just because we feel pride in taking care of our elders... It was like looking after an old man who is like a baby at home. He did everything according to his own choice. He ate when he felt like. He got up when he felt like...Everything he did according to himself. He needed attention all the time just like a baby. We can scold the children but we cannot say anything to the elders. One cannot say no to them.

Nasreen [female, 45-49 years, long-term condition]

The use of “social help” was not inevitably stigmatised. For long-term sick Babas and Valdas who were secure and had children who displayed their *khidmat* in other ways, care services were felt to be helpful and not morally laden; and they were the only source of care for individuals who had slipped through the net of family care, as for example those who were unmarried or divorced or had children who were *laperwah* (irresponsible). Moreover, the experiences of the informants who had contact with care services and home help suggest that any reluctance to rely on care services was borne not only of an ethic of “looking after ones’ own” but also, overwhelmingly, by

negative experiences of the assistance provided by social services. The accounts resonated strongly with those given of the benefits system discussed in Chapter 7; accessing care services was felt to be a “hassle” and the informants were weary of “fighting against the system”; there was a pervasive perception that the system only worked for cheats who acted up the severity of their health conditions, and that those who were genuinely in need and naïvely played by the rules were excluded from care.

As I discussed in Chapter 7, the complaints express the informants’ marginalisation in relation to the state. In addition, however, some individuals harboured specific reservations relating to the cultural appropriateness of the care provided by social services. Much of this related to their orientation towards the ethnicity of the caregiver provided. They often said that care services were compromised by the lack of Urdu- or Punjabi-speaking caregivers. Some of the informants also expressed the desire to have carers who were Pakistani (or at least Asian) because of the sense of shared understanding or “easy feel” that came from being looked after by *apna admi* (one’s own). Mazhar, for example, requested an Asian carer instead of the Black carer he was originally given: “I told them to give me someone who is *apna admi*, one who is of my temperament. That is Allah’s wish. Pakistani or Bangladeshi. Anybody, but somebody who understands my temperament...” (Mazhar’s particular aversion to the Black carer may perhaps be borne of racist sentiment – ‘Black on Black’ racism was alarmingly common in East London). As well as ethnicity, the gender of the caregiver was also very important. For Rafia, receiving intimate personal care from a male carer was an affront to Islamic values and a source of deep shame (*sharom*).

8.5. Household maintenance

Long-term ill-health also impacted upon the household’s capacity for routine household maintenance by compromising the sick individual’s ability to complete their expected domestic roles – obviously, ill-health among women in particular. Household maintenance was an important dimension of the household’s social status. Domestic maintenance tended to be labour intensive. In general, the informants had exacting standards of cleanliness, and the delegation of housework to the middle-generation women in the household often meant that other family members did little to minimize the domestic work they created. For example, they might leave their dirty plates on the table, leave rubbish lying on the kitchen surfaces or cast clothes that had only been worn once into the washing basket, safe in the knowledge that somebody else would pick them up or wash them later on. Many of the informants felt that this was an area of cultural

difference: “in the Asian culture because I think the women do so much for the husband and kids cause they’re not working, I think in a way it spoils them to an extent that it actually makes them quite lazy afterwards”. The level at which the household reproduced itself, its cleanliness, state of repair and the quality of the food consumed, were important for status-production and differentiating between households, and as before, were dependent on unpaid female labour.

In two of the households, ill-health in the primary female caregiver had led to domestic tasks simply being left undone, which created a lot of subjective stress and made everyday life increasingly unmanageable. Nafisa’s household was in such a poor state of repair that her two-year old son ran onto the main road through a door with a broken latch and nearly got himself run over. The family came to the attention of “the social”. Social services found the flat so dirty that they gave Nafisa a vacuum cleaner, washing machine and wardrobes to contain the overflow of clothes. Subsequently, the flat became infested with fleas, which hopped in the hundreds out of the curtains and carpet, and the pest control were sent for. Nafisa was classed as an unfit mother and social services threatened to take her five small children into care. Her relatives called her a “gyppo” (*moorey*) and avoided going round to visit. The material consequences of leaving household work undone could therefore be great.

8.5.1. Negotiating housework between spouses

As I suggested in section 8.4.1, there was generally little flexibility in the performance of housework between spouses. Ill-health among the female informants rarely changed the gender division of domestic labour. Men’s income-earning roles were prioritised over giving additional help at home; productive work was valued more highly than reproductive work, which meant few shifts in men’s domestic roles, and women were often unable to relinquish housework despite long-term ill-health. The female informants were at pains to emphasize the value of their household work. Shaheen said pointedly that “all of a sudden when I get ill and *then* he [husband] finds it hard to cope... when I’m in bed for three days, everything gets turned upside-down”. Male income-generating work was thus underwritten by unpaid female domestic labour, carried out under circumstances that were potentially prejudicial to the woman’s own health, which ensured that the men were free for employment.

If there is no flour he’ll tell me to make rice instead of going out to get some. He’ll tell me to get it when I’m better. He doesn’t help me with anything other than bringing in the money. // He’s good at just two things – work and sleep.

Iram [female, 50-54 years, long-term condition, translated from Urdu]

Men's responses to their wives' health conditions were strongly affected by taken-for-granted gendered household roles. Men did commonly take on greater roles in aspects of household work that involved interaction with the outside world, particularly general household shopping, when circumstances permitted. In particular, men typically took responsibility for the meat shopping – a potent symbol of provisioning. Nasreen admitted that “I don't even know how to buy the meat because my husband does it all!”. Role shifts were also constrained by ideas about men's capacities – for example, men were often assumed to be incapable of doing skilled domestic work such as cooking. Some of the female informants did challenge their husbands over domestic work, but even if they won the odd argument they were usually unsuccessful achieving long-term change. For example, Iram's husband was quite unrepentant: “when I'm not well I don't say anything, but when I'm well I fight with him. But what's the point of getting angry?”. However, women could themselves be reluctant to relinquish housework in a context of limited alternative sources of prestige and security. Their expertise in housework was a way for women to secure centrality in the household. Consequently, when the long-term sick men attempted to take over more domestic work in the search for valued social roles outside employment, many of the wives were reluctant to let them do so. Razzaq liked to help with the housework because it made him feel that “time goes fast”; however, his wife Haseena complained that when he did so the plates were still greasy at the end and there would be puddles of water all over the kitchen.

I used to suffer severe migraines when I did something, but I was still cooking. Cos I knew my husband was gonna come home and he would want his dinner.

Shaheen [female, 45-49 years, long-term condition]

He's started doing a bit of housework, doing the washing up just to keep himself busy. He goes up and down the stairs, putting things away, doing household work, to keep himself occupied. It gives me so much pain to see him like that.

Nighat [female, 50-54 years, family member, translated from Urdu]

8.5.2. Negotiating housework from others

Rather than challenging gendered norms about the performance of housework, most of the households developed competent routines for household maintenance through informal claims over the labour of children or people in other households.

8.5.2.1. Children as ‘young carers’

The children of long-term sick mothers were more likely to be drawn into the work of providing *khidmat* or substituting for housework than the children of long-term sick fathers, who tended to be looked after by their wives. Within families, certain children were also more likely to become involved in housework than others. Sons were much less involved than daughters, and generally it would be the eldest daughter who took over the mantle of domestic responsibilities (the *baji* or eldest sister). In Shazia’s case, the two eldest daughters had “gone astray” and at fourteen, the third daughter Asma had taken over the housework. Asma was actually a highly competent young woman who managed the work of cleaning and cooking for eight people alongside her homework and chatting with friends on the internet with maturity and good humour. I observed Shazia chivvying Asma through the housework on a number of occasions, chasing her up the stairs with the laundry basket shouting “if you leave them in a heap how the fuck are they going to dry? I can’t take this any more, I’m ILL, nobody lifts a finger to help me”. On one occasion Asma’s tardiness in cleaning up the kitchen was so frustrating that Shazia burst out with “I earn all the money in this house, do I have to do all the housework as well? The doctor’s saying that I shouldn’t get stressed. Are you trying to KILL me?”. She was engaged in a continual re-legitimation of her ill-health, reminding the girls every day of her reduced capacities and how their laziness made her stressed and therefore even more ill. However, she once also turned to Asma and acknowledged that “you’ve had quite a lot of pressures haven’t you, with my illness and looking after me and cooking for the girls and cleaning and you’ve got your education and all that... you’ve lost your childhood, haven’t you”. She had complicated feelings of guilt at demanding so much from her daughter and at failing to live up to her own ideals about motherhood and sacrifice, illustrating the discrepancy between norms and behaviour.

8.5.2.2. Transfers of domestic work in the moral economy of kin

Households affected by long-term ill-health could also informally claim assistance with housework from the moral economy of kin, including adult children and wider *biradari* members. In functional terms, adult children’s households were inter-related meta-units arching over several nearby households centring around the “main house” where the parents lived. Local kinship and inclusive household boundaries allowed for dense and multiplex flows of household work between households affected by long-term ill-health. Zulfikar and Noor Jahan, for example, lived on their own in a block of flats that was provided as sheltered housing by the council, with

matrons and nurses on hand in case of any problem or emergency. However, their youngest son and daughter-in-law lived a 15 minute bus ride from them, and the daughter-in-law performed much the same domestic work as she might otherwise if they had all been living together. She came round in the mornings after her husband went to work, and spent all day with her in-laws in the flat, helping with the cooking and cleaning and giving them company, sitting with them and watching the Indian serials on TV. In the evening when her husband returned from work they ate together with Zulfikar and Noor Jahan. Zulfikar said that “she’s quite a good cook also like my wife, and she takes care of my coffee at half past ten o’clock, she’s quite particular... quite helpful”.

Informal assistance with domestic work took on a greater importance for those who were not living with spouses or who could not rely on adult children. Claims to assistance with housework were mediated by the normative expectations around support through the bonds of relatedness, and also through affective ties. Ghafoor and Ashraf were Babas who were both on their own – one divorced; one widowed – and incapable of looking after themselves due to their ill-health and never having learnt any domestic skills. In his early 60s, Ghafoor had at last learned how to cook for himself. He listed the menu of items he had learned to prepare since his wife had left him: Weetabix, sandwiches, rice and lentils, ready-made heat-and-eat meals from Tesco, mashed potatoes and beans; “mostly English things, not very complicated, mostly heating from the pot”. They both managed to get by with transfers of domestic work from male bachelor friends who lived nearby, who they attempted to repay by giving them meals, illustrating that friendship could substitute for kinship if needs be.

Many of the informants compared the nature of informal domestic assistance unfavourably with Pakistan. They often expressed the sense that social life had lost ‘thickness’ in the UK. Everybody was “busy” and “in their own homes”: “they all work, nobody has time”; “over here, everybody is selfish”. As Yunus complained, “sometime they come round for dinner, ‘wow, what lovely food you have made’; that’s it then they go”. The thin and venal nature of sociability in the UK was contrasted with the dense *milna-julna* and *aana-jaana* (coming and going) of life in Pakistan, where people would pop round spontaneously and offer assistance in a natural way.

Back home, where I live there is 350 houses all related together, uncle aunties cousin and all together. No-one’s different like Black person or White person, or any other outside. And they know you. If something going on and they’re ill, then if during daytimes and even nighttimes so you need lots of help, you don’t feel that you are only one person struggling... You know even

friend come round they don't just sit there and watch, they help you. If she needs you know, need to go bath and clean up and stuff like that they help you without asking. It's a different life there, different life.

Haseena [female, 35-39 years, family member]

As I suggested in Chapter 7, the informants' networks of kinship-come-friendship were not as harmonious, interdependent and stable as they have been presented in the literature (see Stack 1974). The informants tended to experience informal assistance as insecure. Access to support with housework was dependent on the strength of ties with relatives and friends. An episode of ill-health didn't necessarily release novel support; if enmity pre-dated the onset of health condition, access to flows of assistance might not change afterwards. The chronicity of long-term ill-health was the key problem in negotiating informal assistance with housework; reciprocity from wider kin was indeed sometimes exhausted. Mehek, for example, lived alone and relied on her sisters, her common-law partner and his brother to help her with cooking, cleaning, driving her to the supermarket and taking the shopping back to her house. She felt that her sisters were running out of goodwill towards her and starting to make excuses. She was aware that she was turning to them more often in need of help than vice versa, and understood their feelings that she was a burden on them: "they try to be friendly and everything... but it's like going back, ennit?".

"Oh don't be stupid, you don't understand we're busy I'm doing this, I'm doing that, I have to do this". They give their excuse to me but... forget it. But then if I said to her "you didn't done this", oh, "we drop you this time home and you are selfish and we done this for you and you don't do nothing for us and" ... You know, it upsets me.

Mehek [female, 40-44 years, long-term condition]

8.5.3. Inter-relatedness of housework with other resources

The level of work involved in household maintenance was dependent on the resources available to the household and principally on housing. For many of the families in social housing, the amount of domestic work required increased substantially as a result of being separated from the Asian enclave. Nafisa, for example, was moved by her housing association from a property in the heart of Forest Gate to a property towards Stratford. She viscerally detested the new flat where life was unmanageable. The flat was in a neighbourhood inhabited by Black people with whom she felt she shared no understanding. Shopping had become a logistic nightmare, having to take the bus to get back to the Asian shops on Green Street and struggle back under loads of shopping.

Nafisa said philosophically that “I never thought I’d find it so hard... it’s so difficult being here and everything”.

Financial resources were another key resource that affected the amount of domestic work that had to be done. Labour-saving devices such as dishwashers or ready-made food could be relied upon to make domestic work easier or to free up an individual for other work. Financial resources meant that a family could pay for a cleaner or domestic help, particularly when it was the primary caregiver in the household who became long-term sick. Transnationalism could also create opportunities for arrangements for domestic work. Economic inequality between Pakistan and the UK meant that in some cases – where the UK family was “getting ahead” – domestic help could be imported from Pakistan, allowing domestic labour to be purchased below rates of payment that are the norm for the UK. Shazia, for instance, had twice invited Noreen and Waris to the UK on six month visit visas. They were poor cousins of her husband who had never had any children of their own. On their visits to the UK Noreen provided domestic help, cooking, cleaning, doing the shopping, sewing *shalwar kameez* for the family, pressing Shazia’s arms and legs and massaging her head with oil. Noreen also did informal paid work whilst she was in London, cleaning several of Shazia’s friends’ houses and sewing *shalwar kameez* for families that Shazia knew. Waris did cash-in-hand work such as leafleting and market stalls.

I can't do the housework and bring in the money, I need Noreen. I asked her to come and help. If the house is clean, the clothes are clean, the beds are done and the chapattis are made then I know I've got a lot of stress but it cuts the stress in half. I know I'm keeping like a servant or a carer but I just want six months of my life where I can go to the gym and my health can come back.

Shazia [female, 35-39 years, long-term condition]

Transnational resources could also be mobilised to enable unpaid arrangements for domestic help. Sometimes families tried to bring over a family member from Pakistan as a solution for the problems raised by long-term ill-health. For example, Liaqat’s mother-in-law came to the UK for his daughter’s wedding and stayed for six months afterwards. Liaqat found her domestic assistance invaluable, especially since their daughter had been doing much of the work before the wedding. However, legal constraints restricted the possibilities for securing such assistance long-term. The British state permits permanent entry to a limited set of kin, while other relatives may be permitted entry under exceptional compassionate circumstances based on pragmatic

considerations (see Harriss and Shaw 2006; Harriss and Shaw 2007). Often, repeated short-term visit visas ended up being a longer-term compromise.

8.6. Childrearing

All of the informants who had children found the work of parenting problematic alongside long-term ill-health. Parents worried about children suffering emotionally as a result of the ill-health and materially due to the ensuing financial hardship. Many of the long-term sick women felt guilty about their capacities as a mother and worried that they had not devoted enough time and attention to their children as a result of being overly preoccupied with their own health. Sayeeda regretted that “I’ve probably been a horrible parent... I just can’t help myself. Instead of giving them more love I know that I’ve given them less than I should have”. Zubia said that her children were like “strangers”; “even my daughter, she still tells me mum when I was growing up, when I needed you, you used to be sick all the time”. Women who had taken on all-consuming roles caring for other long-term sick people also felt guilty about having not prioritised their children, reflecting women’s multiple caring roles and tensions between their responsibilities to their marital and natal families. The long-term sick fathers talked about missing the physical aspects of parenting young children; participating in their children’s activities, rough-and-tumble games and outings. Ismail said of his childhood with a mentally ill father that “a normal family won’t know what it’s all about. The things that they got going for them is all, happy days”.

The greatest problems with parenting were described by the mothers who were suffering from mental health conditions. They described episodes when they had neglected their children and even endangered their children’s lives. Umbreen and Guriya had left their infant children alone in the house and wandered dazedly around East London, talking to themselves and wearing non-matching *shalwar kameez*. Their husbands were both at work at the time; Umbreen’s husband left work and began to stay at home after he became aware of the danger that his children were in. Guriya felt that she had recovered following her psychiatric treatment, and was now more responsible as a parent; but had nonetheless internalised the idea that she was a distracted, neglectful mother and didn’t like to be left alone with her children. Parents had strong concerns about the effects of their mental illness on their children’s mental health and wanted to protect them. In two cases the parents had been quite proactive about contacting social services or the child and adolescent mental health team.

In cases of very severe mental illness, there was a salient fear that “the social” might judge parents to be incapable of parenting the children, separate them and put them into care. As is often found in families threatened with child removal, social services were regarded with a strong mistrust (see Ramchandani and Stein 2003). In this case, however, the mistrust was also intertwined with the identification of social services as a White institution (*gori hukoomat* or White government) that was felt to interfere excessively in the rights of parents to bring up children in the manner they saw fit. As Zubia said, “our right is to raise our children in which way society and religion asks you to make them a good human being... these things the government and these laws have taken away from us”. The mistrust of social services was a factor contributing to Shakil’s decision to withdraw his wife Billo from treatment for her mental illness: “instead of helping us they got on my case and started coming after me about how well the children were being looked after, so I told them to get lost”.

Overwhelmingly, parents managed to get by with the support of others in the family and community. Wilson emphasizes the extensive flows of help with childcare that pertain between sisters and sister-in-laws in South Asian communities (Wilson 1978). However, in this study, support from matrilineal kin was found to be more significant in managing childcare needs than the support of in-laws, as Ayesha’s account shows.

My brother became my kids’ mum for a little while. And even now he says to me, I’ve taken care more of them. He says, I have the right to tell them off and you can’t tell them off, because he says I was a mum to them more than you... He used to throw their nappies out, make them feeds. Even, even now when he sees that I’m doing something else and I’m busy or there’s a phonecall he will make them food.

Ayesha [female, 20-24 years, long-term condition, speaking of her younger brother]

Relationships between sisters and sister-in-laws were less productive of childcare support, and tended to be more characterised by competition. Even though Nafisa was not working, she resented the idea that her sister-in-law would profit from her inactivity by going out to work and leaving her children at her house. The provision of childcare was therefore not as fluid or unproblematic as has been suggested in early studies (see Young and Willmott 1957). The difficulties that the informants had in reciprocating practical support meant that some were reliant on paying for childcare, even when it was provided through the same informal networks; reflecting how social ties were threaded by material considerations. Fiza complained that “I asked my friend if they could look after my child and she asked me to give her £15 a week”.

Another salient concern for parents was providing financially for their children, who were major consumers in households and a very significant source of financial stress. Parents in households that were “going down a few notches” after the onset of long-term ill-health had painful anxieties about the impact of poverty on their children’s development, on their children’s self-esteem and ability to have and take part in the same things as their peers. Being able to provide materially for children was also an important part of the status-production work of parenting. For Safuna, for example, it was important that she should buy gifts for her grandchildren that were from branded shops such as Mothercare and BHS rather than from the market stalls, as her daughter tried to encourage her to do. Consequently, spending on children tended to be privileged within family budgets, as I discussed in Chapter 7, and parents, particularly mothers, would scrimp on their own personal needs in order to provide for their children. This is illustrated by the moral high ground staked out in Sadiq’s account.

Alhamdulillah (praise be) my wife is really lovely, she doesn't make too many demands on me. The children when they were young alhamdulillah we bought them whatever we could afford. Whatever we could afford, we gave to them.

Sadiq [male, 60-64 years, long-term condition]

Most of the parents did their utmost to protect and shelter their children from the negative effects of long-term ill-health, by managing stoically, concealing problems and not asking their children for help. As Nafis put it, “we try not to let the children know, but they can tell from our faces and then they become stressed as well”. Sons were sheltered more from the effects of chronic ill-health than daughters, which seemed to be partly to do with the general importance placed upon sons (Purewal 2003), partly to do with gendered practices around spending time at home versus outside (Bhatti 1999), and partly to do with the strong affective ties and friendship and sharing that often existed between mothers and daughters. Similarly, elder children would be sheltered less than younger children, as, normatively, being the eldest child entailed additional responsibilities in the family. The responsibilities of eldest sons were distinct. In several households in which a father was very profoundly incapacitated by long-term ill-health the eldest son ended up taking on the role of “the man in post of the house” during his teenage years. This involved taking on specific ritual responsibilities at *biradari* gatherings, representing the family at weddings, funerals, meetings held to make important decisions, and in prestations of *lena-dena* (see Chapter 7). Interestingly, the eldest sons themselves had some ambivalence towards taking on the role of household head. Although they found it time-consuming and sometimes boring,

they appreciated the maturity that was engendered by engaging on an equal footing with the Babas. Asif reflected that “at the age of 16 I could converse with a 16 year old, I could also converse with a 65 year old, very comfortable”.

The informants also identified certain positive effects of long-term ill-health on their parenting. Long-term sick men who withdrew from paid employment particularly appreciated being more involved in their children’s lives as a result of spending more time at home. Immersion in fatherhood was an important route through which men could take on valued social roles after losing their self-identities as workers and breadwinners. Yasin, for example, gave long and detailed descriptions of his sons’ routines and how he interacted with them over the course of the day. “These kids, they keep your day full”. His intimate knowledge was an expression of the vocation he had found in fatherhood, which had increased since he had stopped working. Some of the informants also noticed positive changes in the children in response to dealing with their parents’ ill-health. They noticed that the children were becoming sensitive, considerate and responsible; they took on more domestic responsibilities and learned the skills of independent household management earlier than other children.

When she’s [daughter] come with me for shopping she say you did not let me lift anything, she says mummy I am normal [laughs] I said when is people look at you, they will think mum is strong and young and she’s not carry nothing, and daughter’s too small! [laughs] And she says no, don’t worry about people. I will carry, because you will get sick. She is a lot caring with me.
Amina [female, 35-39 years, long-term condition, speaking of her 10 yr old daughter]

Finally, another positive consequence was that children were more likely to grow up to “respect their elders”, which was a very significant diacritic of Pakistani Muslim identity. Many of the informants expressed the sentiment that it was only through witnessing first-hand the provision of *khidmat* and taking part in it at an early age that children could truly internalize and grow to espouse the values of Pakistani Muslim society. Moreover, above the concerns with living up to moral values and expectations, teaching children to respect their elders was also very important as a practical livelihood strategy in preparation for a parent’s own old age.

The children see how you look after your elders and they learn from it. The third generation has become very caring. They know how to look after their elders. My son watches a lot of TV but he still says “we can’t say anything bad to our elders”.

Nusrat [50-54 years, family member, translated from Urdu]

That's where she [mother] gets so angry because she's saved up... everything was supposed to be for her kids like whatever she's thought of, she always thought of us before herself and she thinks that it hasn't paid off.

Ayesha [female, 25-29 years, family member]

Parenting was therefore an area in which the informants struggled with determination, and succeeded to bring their children up well and maintain their dignity and honour.

8.7. Educating children

The home environment and parental support are crucial to children's educational success and have also been critical inputs to social mobility among South Asians in the UK (see Bhatti 1999; Modood 2004). The informants expressed strong concerns about the impact of long-term ill-health on children's education. Generally, long-term sick parents were strongly committed to children's education. Education was seen as a route for children to secure a better future for themselves, in contrast to the underemployment and discrimination endured by the older generations. Kamran said of his son, "he should study, because we have suffered ourselves". Education was also valued as status-production work. It was a significant marker of "getting ahead", and information about children who had obtained Masters degrees or qualified in medicine or law was volunteered with visible pride. Amra, for example, said of her father that "he's got his friends, their children he sees them doing good, achieving grades and degrees and so he expects me to do it as well so that he can go out and say openly and with honour that my daughter she's done this and she's done that".

The informants' concerns about their children's educations centred around absenteeism from school, not completing homework because of their domestic responsibilities or because of a stressful household environment, and the worry that children would be tired and distracted when at school. They had concerns that children were growing up, in Naheed's words, with "old heads on young shoulders", and that this was setting them apart from their peers at school who were unable to relate to or understand their experiences. They had perceptive anxieties about the social difficulties their children were experiencing at school, and the ways in which these were further de-motivating them from their studies. Some said that their children had been victimised or bullied because of their family members' health conditions, particularly when this was a

stigmatising condition such as mental illness, or a visible disability or deformity. Haseena's son had even ended up in fights.

My older son he's quiet, he never talked nothing. And then in this road quite a lot of peoples, the Asian peoples, they go in the same school. And the kids didn't like it at all because they talk, the [other] kids talk. And my youngest one who's 11, he all the time complains that people are talking about his dad. And I try to explain to him that your dad is doing whatever he's doing, he's ill, he's not doing anything it's his illness is making him do that. But sometimes it's hard to explain to kids because they [the other kids] talk ennit and they [her kids] don't like it. You know, about what happens back home. He says in the other peoples' families, I don't know what's going on, so why do they say that your dad is mental, your dad is ill?... Twice he had a fight in primary school, he had a fight because some other boy was saying something.

Haseena [female, 35-39 years, family member]

Parents in households that were experiencing income loss in the aftermath of long-term ill-health worried about the impact of poverty on their children's education. Financial hardship could mean major disruptions in the children's lives, such as becoming homeless, being put on the waiting list for local authority accommodation, and being moved "from pillar to post", creating problems for school attendance. It meant not being able to provide children with resources to support their education such as books, computers, the internet and school trips. The impact of financial hardship on children's education was particularly great at the transition from secondary to tertiary education. For example, Mumtaz's youngest son had underperformed the first time he attempted his A-levels, when his grandmother was diagnosed with terminal cancer. He then missed so much college during his A-level re-takes when Mumtaz suffered a severe episode of ill-health that the council had threatened to take away his educational maintenance allowance. He intended to go to university after completing his A-levels, but wanted to delay his application for the foreseeable future in order to earn money to support his household. Children who were in university were overwhelmingly funding themselves through student loans, and most were studying in London and living with parents. Parents sometimes expressed irritation at the benefits system for cutting child benefit after the age of 18, even though children continued to depend on their parents throughout their time in full-time education, and remained a net financial stress well beyond 18 years.

In general, and in keeping with the ethic of encouraging education (Modood 2004), the informants' accounts showed them doing their utmost to protect and shelter their children's

education from the negative effects of long-term ill-health. One of the reasons why children were so rarely drawn into involvement in care was because their parents wanted them to be able to concentrate on their homework. Parents protected children from knowledge about their health conditions, fearing that they would become distressed and that this would negatively impact on their education. Parental sacrifice of all kinds was considered worthwhile if children secured a good education – a source of dignity and pride, and a quintessential sign of “getting ahead”.

I had this obsession (junoon) to make my children study. I took care of the fact that there are no obstacles in their path of success. For this I tried to appear very happy to them. Even if I used to be very tired I used to wear lipstick when they were to come to me so that they think that I am feeling good, so that I could look fresh. I did not want them to know that I am not well. I did not want them to worry. I always told them to think about their goal, what they have to do in their life. I am thankful to God (Allah ka shukar hai) I have been granted my wishes. Whatever I asked God, he gave me that. Fortunately my illness did not hinder in the progress.

Nasreen [female, 45-49 years, long-term condition, translated from Urdu]

8.8. Arranging children’s marriages

Finally, long-term ill-health influenced the motivations, likelihood and means of arranging marriage for the next generation, and thus impacted upon the completion of the domestic cycle. The significance of the informants’ concerns about children’s marriages cannot be overstated. Parents were only able to feel contented with their lot in life after successfully marrying their children and seeing them get settled, preferably with children of their own. The moral duty of marriage was explained and legitimated with reference to Islam and Pakistani culture. The informants often said that it was *farz* (religious duty) for parents to get their children married and settled before they died, and quoted the saying that parents who did not manage to marry their children would not get *jannat* (heaven or salvation). Parental ill-health could intensify the need for a daughter-in-law to do *khidmat* (service) for them and look after them. Female labour would be relied upon and exchanged between families through marriage, rather than a long-term sick man or male carer taking on domestic work. Furthermore, after the onset of a parent’s health condition children’s marriages might be arranged early or dates brought forward so that the parent would be able to see their child married before passing away. In Ferdouz’s case, after she had put off getting married for ten years, her marriage was arranged from start to finish in two weeks after she found out that her father had been terminally diagnosed with cancer.

I want my daddy to see me married and settled now. I don't want to give him any more stress because it's not good for him. He needs to see me married so that he can be in peace. So I agreed to this rishta (proposal) when it came. Let's see what happens. I want the marriage done as soon as possible.

Ferdouz [female, 30-34 years, family member]

The most significant area in which long-term ill-health impacted on the marriages of children was through the spectre of stigma. As I suggested in Chapter 4, stigma had the potential to spread to the entire family, not merely to the individual who was afflicted by long-term ill-health. Parents and children often feared that the presence of long-term ill-health in the household detracted from the children's marriage prospects and that the family would have difficulty in securing a *rishta*. Safuna feared that "there are doubts and I really worry about whether my daughter-in-law will accept my husband and me... I mean that maybe when she sees his illness then she might not tolerate". In such situations, it was common for families to rely upon their transnational kin for a show of solidarity. For example, Sayeeda's daughter was going to marry a cousin from Pakistan rather than somebody "outside" the family, despite the medical warnings against consanguineous marriage due to the hereditary cancer that was running in her family: "it's hard for us to find a spouse from outside because of this condition because people in Pakistan they talk, they think that it's like something in your family... They don't say it in your face but you do hear a lot of things. They say er... *oh lok bimaar ne* (those people are ill)". Similarly, in Ismail's family "the view was, who's gonna marry you children... who's gonna marry somebody who's father's like this"; but all three sons eventually married cousins from Pakistan: "at the end of the day we had the *rishtedar* (relatives) coming there for us".

For most parents, the search for a suitable *rishta* became a major preoccupation once the children started to grow up (became *jawaan*). As Yunus said "you know our culture; till the children are married one stays worried". Many of the Babas had not worked for a long time, and increasingly their status was marked out through the marriages of children rather than through their own occupational status; weddings expressed and were generative of a family's social standing. Werbner describes British Pakistani weddings as competitive potlatches within the moral economy of the *biradari*, through which the economic status of the family is embellished and extended through the ostentatious display of the ritual (Werbner 1990a). Charsley shows that wedding styles convey complex value-laden messages about the affluence, modernity, cosmopolitanism or religious orthodoxy of the family (Charsley 2003). The financial costs of

marrying children, especially daughters, were therefore a major strain on households experiencing income loss in the aftermath of long-term ill-health.

Plate 23: Displaying the wedding gifts, East London, 2004. Gifts from the bride's side (*dahej*) and groom's side (*bari*) were shown to *biraderi* members and friends of the bride.



Source: author's own.

Rather than scrimping on the rituals, the informants prioritised and budgeted for weddings, and took loans from friends and relatives in order to be able to put on an appropriate display. In many cases, adult children who were in paid employment were saving up for their own weddings rather than expecting their parents to pay. Nasreen's sons paid for half the cost of her daughter's wedding, but she believed that it would have been inappropriate for her daughter to contribute: "what was she to share – she has to just study". In other households the taboo against accepting money from daughters was overlooked, and the daughters were saving up for their own weddings. This granted the *Idher ki* an additional degree of independence. Shanila chattered excitedly that "I'm starting to save up now because Asian weddings cost a bomb! I think of my dad and he's 52, he can't work for the rest of his life and the wedding's going to cost £25,000 then you know... they've set money aside, a whole wedding fund but obviously if you want little things and big things then they cost!".

Finally, as Ahmad also points out, the quality of the performance of the rituals at a *khushee* (happy event) also connoted status (Ahmed 2005). It was important to Nasreen, for example, that she had pulled off her daughter's wedding in style despite her deteriorating glaucoma. She managed to hide the symptoms with the support of kin and friends: "with God's grace I managed to marry her with my own hands".

I used to feel a bit worried that my children do not lag behind due to my illness. I have always worried this and for instance during the marriage I had called my relatives to my place... then all of a sudden my vision seemed to disappear. I felt that I had gone blind [starts crying]. But I worked by feeling my way and using my memory. I did not tell anybody about this. I was scared that if I tell them then they would take me to the hospital. So I took medicine and I kept going by feeling my way around.

Nasreen [female, 45-49 years, long-term condition, translated from Urdu]

8.9. Conclusions and implications

This chapter explored the reproduction of the households of the long-term sick informants. The need for care and the restricted capacity for domestic work required households to develop competent routines to ensure the day-to-day family care, household maintenance and family reproduction. However, the routines also influenced the households' longer-term status and security; namely, the extent to which household members were able to produce moral values in accordance with the normative expectations bound up in belonging to Pakistani society (*maashra*).

The chapter found that the consequences of ill-health for reproductive work were inherently connected to the position of the household in the system of production. The informants' socio-economic position was important in setting the level at which the household was able to reproduce – structuring the status that could be gained through marriage alliances and wedding rituals; the labour-intensiveness of everyday household maintenance; and constraining the capacity to "get ahead" via the socialization and education of children. However, the informants' structural position as transnationals with interests in both Pakistan and the UK presented a valuable resource in this regard; the economic advantage that they had over branches of their families in Pakistan secured claims over kin for marriage and domestic work.

Furthermore, the informants creatively interpreted and reproduced cultural ideologies concerning *izzat* (honour or prestige) to engage in status-production work to compensate for or counteract the downward economic trajectory into which many of their households were falling. They were able to gain in status on local, emic terms, by making marriage alliances that met with approval from society (*maashra*); by performing *khidmat* (care) in accordance with normative, gendered expectations about household roles, espousing chaste upper-class religious identities from Pakistan; by maintaining the home nicely; and by investing in child-rearing and children's education. Within limits, therefore, the informants' everyday strategies for household reproduction represented a form of cultural resistance to the material reality of having "gone down a few notches", allowing them to pursue a multi-layered form of social standing linking together their means of production, consumption and reproduction. The informants were not, however, merely following cultural norms and values, but interpreting, reproducing and contesting them in accordance with the limits set by inequalities of resources and power within their immediate local worlds.

Chapter 9: Conclusions

bhooke maran marasi, aproo shah aa gaye

the marasis are dying of hunger, now the shahs have come down to stay – Punjabi saying

9.1. Introduction

In this study, I examined the experience and consequences of long-term ill-health among Pakistanis in the UK. Pakistanis have a disproportionately heavy and premature burden of long-term ill-health and, as attested by a wealth of evidence, are frequently marginalised socially and economically. The material consequences of long-term ill-health emerged to be extreme, and a more immediate and pressing part of the experience of ill-health than for the more privileged groups that constitute the empirical base of much of the chronic illness sociology. In a stark departure from the literature, to understand the experience of long-term sick Pakistanis I turned to the classic concept of the sick role, which gave conceptual purchase over the practical, everyday consequences of living with ill-health, over its psychological meanings and significance. To understand impoverishment and how households attempted to resist the material impact of long-term ill-health, I turned to the concept of the livelihood. To understand the detrimental impact of long-term ill-health on certain households, the analysis needed to be grounded in the institutional structures of the local labour market and the state. However, in Pakistani households, where roles and responsibilities are strongly differentiated by gender and generation, the impact of long-term ill-health on the households' means of production, consumption and reproduction also needed to be unpicked, and the links between them exposed.

This final chapter draws together the main findings of the thesis by revisiting the research questions introduced in Chapter 1. It turns to the issue of “how, where, why and under what circumstances” (Archer 2003) (p.20) ethnicity comes to be important in the patterning of ill-health and its impact on livelihoods, drawing on the flexible but concrete formulation of ethnicity as social practice that I developed throughout the thesis. Finally, I conclude by suggesting some practical recommendations that arise from the study.

9.2. Revisiting the research questions

This summary draws together findings from the quantitative and qualitative components of the study, and identifies some of the complexities in integrating approaches which make strikingly

different epistemological assumptions about long-term ill-health, livelihoods and ethnicity. As I discussed in Chapter 1, the motivation for mixed-methods approaches is to examine the convergence or confirmation of results across different methods (Morgan 1998). In this study, the combination of methods provided complementarity rather than direct confirmation. There were instances where the results confirmed one another or diverged, or where the quantitative findings set a problem for the qualitative research or vice versa. I examine these points of complementarity as I run through the research findings.

The findings of this study are undoubtedly affected by the methodological, local and historical dynamics at work in the data. However, I have discussed these factors explicitly in the chapters of this thesis, and I would argue that the findings are relevant and conceptually generalisable beyond the immediate context of the study. Indeed, as Wainwright points out, “generalisability depends not just upon detailed description of a phenomenon, but on revealing the social relations that underpin it” (Wainwright 1997) (p.15).

9.2.1. Social process of long-term ill-health

The quantitative analysis in Chapter 3 showed that long-term ill-health was more common and more severe for Pakistanis than for people from all the other major ethnic groups apart from Bangladeshis. At the household level, the heavy burden of long-term ill-health among Pakistanis was even more evident; nearly half of working-age Pakistani households contained a long-term sick adult, and the extent of clustering of long-term sick individuals in households was also greater than in the other ethnic groups. In keeping with these quantitative differences, the ethnographic study found that the relative commonness and normalcy of long-term health conditions lessened the disruption they caused to individual biographies. This was particularly the case for diabetes and heart disease, which felt less serious and life-threatening than other conditions. Equally however, the clustering of long-term sick adults in the household and local networks constrained the social responses that could be made to any individual case of ill-health, making it more difficult to provide financial transfers or practical assistance, and exacerbating the material consequences.

The quantitative analysis also showed that the higher levels and premature onset of long-term ill-health among Pakistanis can be explained largely in terms of their disadvantaged socio-economic position compared with other ethnic groups, confirming a large body of social epidemiology. In the ethnographic study, the structural antecedents of ill-health emerged as important contextual

influences over the social process of becoming long-term sick. However, two contradictory patterns were evident. For some of the informants, the background of poverty and insecurity was reflected by a psychological robustness and tendency to “get on with it”; the significance of ill-health faded in relation to all the other problems they had to deal with. Socio-economic status thus conditioned the degree of ill-health that must be endured before a person could step into the full social role of being long-term sick (*mareez*). For others, however, the context of perennial hardship deepened the preoccupation with ill-health; the accumulation of stresses made it harder to “take control of” a long-term health condition, and there was little prospect for empowerment and resistance to the sick role.

Interactions with other people were strong influences over whether an individual came to regard themselves and be regarded by others as long-term sick. Health professionals were particularly important as gatekeepers, providing diagnoses that legitimated the informants’ subjective feelings of ill-health and made them socially meaningful. The informants’ Pakistani ethnicity often seemed to influence their interactions with health professionals in negative ways. Their marginalisation from the health professionals, on the basis of class and ethnicity, delayed the effective diagnosis of their health condition. The informants’ subjective experiences and presentations of ill-health also diverged systematically from biomedicine. The overwhelmingly poor experiences of state healthcare meant that the period of uncertainty about the nature, meaning and prognosis of ill-health often dragged on, and made it harder for people to “get on with” coming to terms with and managing ill-health.

Interactions in the everyday arenas of home and community, or ‘local worlds of experience’ (Kleinman and Ware 1992; Kleinman, Wang et al. 1995), emerged as pivotal to the process through which long-term ill-health became socially meaningful. The practical consequences of long-term ill-health were substantially produced and managed within the family, to the extent that I suggest that the family should be seen not only as the location or set of people most directly affected by long-term ill-health, but also as *constitutive* of the social reality of ill-health. Ill-health required negotiations around dependency and claims to care from others, and was therefore embedded in socially-defined hierarchies of power in the home:

- I. **Generation** – the Babas and the Valdas were able to inhabit a sick role more comfortably than the younger individuals, as ideologies surrounding respect for elders, filial obligation and the sacrifice the elders had undertaken as labour migrants gave them legitimate claims to being dependent on other people.

- II. **Gender** – stoicism was a key part of local masculine and feminine constructions of the sick role, but whilst feminine stoicism emphasised *sabar* (steadfastness) and sacrifice for others, men were able to claim a more open display of dependency by virtue of the greater command they had over others in their households.
- III. **Household roles and responsibilities** – individuals whose everyday activities were particularly indispensable to the household system had less access to the sick role.

Elaborating on the Kleinmans' work (Kleinman and Kleinman 1985), the data here show that the social process of becoming long-term sick is contingent on the *implications* of sickness, in the context of structural arrangements of power in individuals' 'local worlds'. However, the informants' accounts suggest the workings of an emic formulation of gendered power that has not been appreciated in the literature on South Asians in the UK. For example, various researchers have argued that British Asians are more likely to take on a sick role than the White majority as a result of a cultural familism that values autonomy less than interdependence, mutual support and reciprocity. They suggest that British Asians are more comfortable with their roles being substituted by other family members in an integrated family system, and therefore challenged less to persevere with carrying out activities independently (Ahmad 2000; Gardner 2002; Hussain, Atkin et al. 2002). Here, however, a more nuanced picture emerged. The fluid substitution of activities was a reality only for powerful groups – the Babas and Valdas, and men in general. For the younger generation, and for women, the key factor influencing the propensity to take a sick role was not an aversion to independence *per se*, but the positive desire to build on their 'centrality' to the family and not be a "burden". As a result of the social structural and cultural conditions of their lives, many of the informants' interests were vested strongly in maintaining gendered family roles rather than being independent, and this was reflected in their lesser recourse to the sick role.

By contrast, the community setting often represented a contradictory or alternative social reality to that of the home, in which individuals managed a different presentation or cultural performance of sickness. In the inter-household arena of *biraderi* (extended family) and *maashra* (society) there was an overwhelming desire to conceal ill-health, which related to the informants' desires to maintain a veneer of normality; the constellation of stigmatising negative cultural meanings connoted by long-term ill-health; and the need to conceal domestic problems, which provided a platform for status differentiation between households. However, the extent of stigma and concealment also depended on the extent to which the informants' interests would have been

threatened by publicly claiming a sick role, and on the extent of their reliance on informal ties of kinship-come-friendship.

9.2.2. Economic consequences of long-term ill-health

The ethnographic study provided a close, detailed account of the ways in which long-term ill-health impacts upon livelihoods. Ill-health incapacitated the long-term sick individuals and made it difficult for them to carry out their everyday roles and responsibilities within the household economy. Ill-health also generated extra reproductive work for care-givers, which created opportunity costs for other economic activities. Unlike other types of economic crises, the effect of long-term ill-health was therefore to debilitate the economic activities of the entire household, resulting in increasing economic polarisation between workless households containing long-term sick adults, and multiple-income households in the rest of society.

Ill-health raised expenditure, through big one-off lump sums for healthcare and housing adaptations as well as increases in regular, everyday expenditures. Finally, ill-health impacted negatively on the moral standing of the household, due to the stigma or self-exclusion associated with the health condition itself; exclusion from the customary standards of “decent living” due to reduced income and consumption; and due to the households’ dependence on transfers from other agencies, which undermined the moral base on which inter-household relationships were founded. The other distinguishing feature of the economic shock presented by long-term ill-health was precisely its chronicity, which made it increasingly harder for the household to recover with time. Many of the households “went down a few notches”, and plunged into a downward trajectory in social standing, which, as we shall see, was a multi-dimensional signifier linking together multiple dimensions of the household’s livelihood.

The quantitative and qualitative components of the study gave some interesting differences in perspective on the question of how Pakistani ethnicity influenced this ill-health engendered trajectory. The quantitative analysis showed that long-term sick Pakistanis were one of the groups with the lowest levels of paid employment overall, and that Pakistani households containing long-term sick adults were the most likely to be completely workless. Surprisingly, according to the analysis of interactions, the relative impact of long-term ill-health on economic activity was no different for Pakistanis than for the other ethnic groups. However, the study showed that ethnicity was nonetheless relevant to the processes through which long-term ill-health impacted upon economic activity. First, to claim otherwise would desocialise and dehistoricise the economic

position of Pakistanis in the UK. The ethnographic study showed that the informants' prospects for retaining and (re)gaining employment after the onset of ill-health depended on the social relations of work in the occupations and industrial sectors prevailing in their marginalised niche within the economy of East London, which was the long-term product of migration histories and past racism. Secondly, the cursory attempt to isolate a 'pure' ethnic effect by treating the effects of cross-cutting socio-economic factors as 'confounding' obscures some of the very processes through which ethnicity operates. The economic consequences of long-term ill-health were differentiated by structural and historical factors, making for some quite specific outcomes for long-term sick Pakistanis:

- I. **Class** – it was not possible to examine occupational class in the quantitative analysis because the high prevalence of long-term unemployment and never having worked meant that the NSSEC was strongly endogenous to the outcome variable of economic activity. However, long-term ill-health was found to have a stronger association with worklessness for poorly qualified individuals. In the ethnographic study, employment relations were found to be central in determining who retained or regained employment in the face of ill-health. People who owned their own businesses and controlled the means of production were somewhat protected from the impact of ill-health. They had access to non-wage income despite incapacity resulting from ill-health, and often they could delegate the management of their businesses to other people. Perversely however, in smaller ventures the economic impact of ill-health for self-employed people could actually be greater than for employees; proprietors lost the personal assets they had invested in the business, and they had no access to sick pay and other fringe benefits. For paid employees, the chances of job retention depended on the employers' interests in keeping them in the organisation, and on the amount of specialised knowledge or expertise they possessed. For unskilled and manual labourers there was lesser contractual job security; job retention depended on the rights negotiated with employers, either through labour organisation or piecemeal, through individual relationships of patronage.
- II. **Ownership of property**– housing tenure stands as a broad indicator of wealth. In the quantitative analysis, long-term sick people who owned their own housing were disproportionately more likely to be economically active than people in rented accommodation. Similarly, in the ethnographic study, property was a key route to financial security, giving people access to non-wage income despite incapacity from work.
- III. **Formal or informal employment** – the thriving grey economy of East London provided informal income-earning opportunities that could be reconciled relatively flexibly with long-term ill-health, often supplementing welfare benefits on a sporadic or opportunistic basis.

Undocumented employment was typically underwritten by multiplex and usually co-ethnic relationships between patrons and employees, which secured informal claims to employment despite sickness or inefficiency at work through ties of obligation, reciprocity and trust. However, informal employment was usually low paid, with no contractual job security, and prejudicial to the weakly-positioned employees.

The position of Pakistanis in the structure of production, and the impact of racism, past and present, therefore, account principally for why long-term ill-health has the effects that it does, in the context the political economy of the locality and of the state.

9.2.3. Coping with the economic consequences of long-term ill-health

The ethnographic study revealed economic responses to long-term ill-health which would be difficult to measure through standard quantitative indicators. Some of the households were able to cope with the reduced returns from wage employment by mobilising their portfolios of material and immaterial resources and engaging in a variety of alternative activities. Not all of the households plunged into a downward trajectory, and the following resources differentiated the impact of long-term ill-health, distinguishing the resilient from the vulnerable households and increasing the economic polarisation within the community:

- I. **Education** – education and skills made long-term sick people and their family members more likely to contemplate employment alongside ill-health and caring, capable of re-skilling and commanding a wider range of alternative occupations. Educated households tended to have a more flexible gendered division of labour, which meant that men and women were more likely to combine reproductive and productive roles and maintain at least one individual in employment, despite sickness and the need to provide care. Education also reduced the extent of dependence on informal claims from family and friends, reducing the need to comply with normative rules and sanctions concerning gender roles.
- II. **Transnational assets** – although in the early phases of the migration process the informants usually accumulated savings in the UK and spent them in Pakistan, after the onset of ill-health the flow of resources across continents might be reversed, and land and housing in Pakistan might be mobilised to support households in the UK.
- III. **Property** – housing often provided a source of rental income; other investments such as businesses, shares and savings bonds, provided additional non-wage income. Such assets could also be sold in response to financial hardship if necessary.

- IV. Welfare entitlements** – the quantitative analysis showed that Pakistanis were clearly disadvantaged compared with other ethnic groups in the receipt of Disability Living Allowance, over and above the other factors associated with the level of financial need for the benefit. By contrast, the ethnographic study identified a complex coincidence of under-claiming, dependence and manipulation of welfare benefits, which were paradoxical expressions of the marginality of the informants vis-à-vis the state. Furthermore, there were ways in which state provision was systematically biased towards normative White, non-migrant families. These problems meant that financial resources from the state were often intermittent, insecure and inadequate to reproduce the family at the level of a “decent life”, and the informants were forced to liquidate their own personal assets to supplement them. Welfare benefits were also supplemented by informal activities such as undocumented work, which created a para-state shadow with respect to welfare.
- V. Strong ties of kinship-come-friendship** – family members beyond the marital couple, usually adult children or parents, were able to “pick up the financial burden” by providing regular wages; taking on responsibilities for specific domestic expenditures such as bills or items in the weekly shopping; and gifting. Households also relied on a dense web of local productive exchanges with family and friends. Informal financial transfers were secured via ideologies concerning inter-generational support and mutual aid, and legitimated through constructions of ‘Pakistani tradition’ and ‘Islam’ as a source of authority or ‘officialising strategies’ (Bourdieu 1977). However, informal claims to financial support were insecure; contingent on the economic status of family members and friends; and the ethic of mutual support was also undermined by the increasing economic differentiation in the community, which intensified competition over social standing. In this context, financial dependence could threaten the moral base on which relations between households were founded, and the informants were often averse to asking for help. Such ideologies were therefore interpreted rather than strictly followed (see Finch and Mason 1993).

These responses served to sustain the economic viability of the household given the weakness of their formal entitlements from the wage economy and the state; the responsibility for reproduction was deflected onto the household and communal economies. However, the potential for coping strategies was strongly dependent on the position of the household in the structure of production; by the nature, range and style of state intervention and provision; and by the material conditions existing in the social networks in which the household was embedded. Economic responses to ill-health were therefore constrained by the structural location of the household and the interdependence between its material and immaterial resources. The scope for variation at a

particular structural position is not to be overly celebrated; households are not able to pull themselves up by their own bootstraps.

9.2.4. Intra-household differentiation by gender and generation

The quantitative and qualitative components of the study produced complementary findings with respect to intra-household differentiation in the economic impact of long-term ill-health and coping:

- I. **Gender** – in the quantitative analysis, the associations between long-term ill-health and unemployment or economic inactivity were found to be stronger for men than for women. The ethnographic study confirmed that male ill-health was taken more seriously and had more of a profound impact on the household economy. However, the poorest households were actually those in which it was a female lone parent who had become long-term sick, or those in which middle-generation women were so profoundly incapacitated that their husbands had become full-time carers. The loss of female domestic labour, combined with the exit of a male carer from employment, made it extremely difficult to maintain household needs for consumption or everyday reproductive activities – a finding that emphasizes the importance of reproductive work for the household economy. Whilst male ill-health tended to be more disruptive to the household economy, female sickness therefore appeared to be more significant in terms of overall welfare.
- II. **Position in the household structure** – the quantitative and qualitative research both confirmed that the presence of young children exacerbated the economic impact of long-term ill-health. The presence of children in addition to one's own ill-health or the ill-health of an adult household member usually meant that caring responsibilities overwhelmed the domestic workload and made it impossible to contemplate employment. This was particularly the case for daughters-in-law and women from Pakistan, because their relative weakness in the household system meant that they were less likely or less able to secure release from their everyday activities.
- III. **Generation** – in the quantitative analysis, increasing age was found to make long-term sick people disproportionately more likely to be out of work. This was confirmed by the ethnographic study, which showed how long-term sick Babas and Valdas were likely to be economically inactive due to a combination of factors: cultural ideologies surrounding appropriate household and life-cycle roles; their limited labour market prospects, given the

characteristics of the local labour market; their skills and employment experience; and the availability of welfare benefits, which made inactivity possible.

Coping strategies tended to be prejudicial to specific household members, both men and women, who found that their time and energy was stretched to its limits by the need to combine both productive and reproductive work. However, women's labour tended to play a more important role in coping with the impact of long-term ill-health than men. Enabling the family to reproduce at an appropriate level required an intensification of domestic labour: more production for domestic use; labour-intensive home cooking, cleaning and washing; and resourcefully mending clothes and repairing items in the house. Female budget-makers tended to prioritise the needs of their children and the preferences of the men in their households above their own personal spending. They turned to their own sources of credit, and the burden of reproducing the family was therefore shifted onto women-centred networks.

9.2.5. Household coping strategies and 'success'

The question of how successfully households affected by long-term ill-health were able to cope is a complex one, the answer to which depends on the perspective taken. Households with property and assets, who were willing and able to engage in unconventional gendered family roles, deeply embedded in and central to their local networks had the most access to alternative sources of income and were the least reliant on state welfare after the onset of long-term ill-health. However, the ethnographic study showed that the informants' own evaluation of their ability to maintain a "decent life" did not depend only on whether they were able to "get by" and survive on the day-to-day, meeting the absolute health needs of family members; but also whether they were able to maintain their internal self-image and self-esteem, "get ahead" and strive towards long-term security and social status. There was competition between households on many fronts:

- I. **Concealing ill-health** – long-term ill-health, like other domestic problems, provided a platform for differentiation in status between households. Many of the informants defined 'coping' in terms of being able to conceal the fact they were affected by long-term sickness. The normative pressures to conceal ill-health depended on the particular health condition, and were particularly strong for mental illness and conditions that were believed to be heritable. The interpretive meanings associated with a particular condition therefore had important practical implications for the experience of illness and the social reactions to the sick person and their family members.

- II. **Taking leisure** – economic inactivity was not inevitably felt to be undesirable. For the Babas and the Valdas, having the capacity to step back from work and be supported by a host of loyal children was well-regarded; it was a sign of prosperity, family unity, and of having successfully brought up respectful and respectable offspring. Similarly, for some women, being a “lady of leisure” was a sign of household prosperity and of appropriate gendered roles being upheld.
- III. **Conspicuous consumption and gift exchange**– the economic impact of long-term ill-health was subjectively experienced as an inability to compete in a symbolic economy defined by participation in conspicuous and novelty-driven consumption. Competitive lifestyle strategies centred significantly around weddings and other *biradari* occasions requiring participation in *lena-dena*, a complex potlatch of competitive reciprocal gift exchange. Although it was possible for the informants to withdraw from this symbolic economy, or create value alternatively, by recourse to Islamic austerity and immaterialism, the cost of eschewing conspicuous consumption was usually great.
- IV. **Status of children** – in most cases, the informants’ implicit life goals were clear, and strongly bound up in their children. They wanted to bring up, educate and marry their children well, and therefore prioritised their children’s needs in budgeting and organising domestic labour. Coping meant not allowing long-term ill-health to hinder one’s children’s progress, the adult children’s eventual destination and their eventual capacity and desire to look after their parents.
- V. **Respectability** – the informants worked to produce the moral values of respectability (being *izzatdar log* or *sharif log*), which took a variety of forms bound up in upholding constructions of ‘Pakistani tradition’: self-reliance, abstaining from state welfare and not asking for help from others; adult children performing *khidmat* (care) for their elders; creating a Pakistani *mahaul* (environment) inside the home; home-cooking rather than relying on “junk” or “English food”; keeping the house nicely and in a good state of repair; inculcating ‘Islamic’ and ‘Pakistani’ values in ones children; and in particular, observing ‘traditional’ gender ideals, including female seclusion and female religiosity.

Households resisted the material and moral consequences of long-term ill-health through the pursuit *izzat* (honour). The findings chime with other recent work challenging the assumed centrality of controlled female sexuality to notions of *izzat*, and highlighting the alternative routes through which Pakistani people lay claim to honour including the positive assertion of religious identities, education and professional employment (see Brah 1996; Bradby 1999; Butler 1999; Ahmad 2001; Ahmad 2003; 2003; Ahmad 2006). However, whilst *izzat* was certainly multi-dimensional, attempts to claim moral status through identities outside of ‘traditional’ gender roles

were contested, and gendered evaluations of sexual virtue were still very important – hence the particular dangers of *awarapan* (looseness) for women.

Notions of *izzat* were embedded in ‘specific regimes of value’ (Werbner 1999) (p.551) and interpreted differently among the informants in accordance with social class and gender. Elite status was sometimes associated with ‘ethnic intensification’ and increased commitment to constructions of ‘tradition’ and ‘Islamic’ religiosity, in keeping with upper-class religious identities in Pakistan. However, for the more secularised elite, higher class status was also associated with having social networks that cut across ethnic boundaries; interests that were less strongly invested in kin and community; and less observance of ‘tradition’, as they had other sources of belonging and fulfilment (see Werbner 2002; Ramji 2005). *Izzat* relied disproportionately on the work of women, who bore responsibility for the ‘good family values’ of their households and living up to constructions of ‘tradition’ and ‘Islam’. *Izzat* therefore emerged as a multi-dimensional articulation of social standing linking together the households’ means of production, consumption and, principally, reproduction.

9.3. Ethnicity: implications and processes

This section brings out the implications of Pakistani ethnicity for the experience and consequences of long-term ill-health. In the ethnicity and health literature, as I suggested in Chapter 1, the implications of ethnicity have been framed in terms of a well-worn debate about the competing claims of material vs. cultural factors. Rather than persist with what Phizacklea has called the ‘phoney war’ between structure and agency (Phizacklea 2000), in this study I followed various theoretical commentaries (Bentley 1987; Moi 1991; Smaje 1995; 1997) in conceiving of ethnicity in terms of Bourdieu’s concept of social practice, which offers a way to grasp the relativity of the effects of ethnicity and the interface between material and cultural factors – which is a crucial, and often missing dimension.

9.3.1. Social stratification

As Ballard observes, the materialist literature on Pakistanis in the UK is “strongly deprivationist in character... rest[ing] on two key terms – racial discrimination and racial disadvantage – which provide the conceptual foundations for almost all current research and policy formulation” (Ballard 1992) (p.484). The quantitative and qualitative parts of the study gave some interesting differences in perspective on the question of social stratification among Pakistanis. The

quantitative analysis showed that the socio-economic position of Pakistanis was disadvantaged compared with other ethnic groups. Furthermore, Chapter 3 showed that structural differences between the ethnic groups were responsible for much of the excess and premature long-term ill-health among Pakistanis, and contributed to the disproportionately high levels of worklessness both for long-term sick Pakistanis and Pakistani households that were affected by adult long-term ill-health. Worklessness among Pakistanis was explained less by the socio-economic factors used in the analysis than for other relatively deprived groups such as Bangladeshis. However, it would be overstepping the analysis to suggest that this was indicative of a strong 'pure' ethnic effect or penalty for Pakistanis; a more likely explanation is that the analysis was able to capture less of the disadvantage of the Pakistanis than the Bangladeshis due to the higher levels of owner occupation among workless Pakistanis and the lesser numbers of workless Pakistanis with no qualifications.

By contrast, the ethnographic study found that socio-economic heterogeneity and stratification among Pakistanis were significant among Pakistanis *per se*, and had an important impact on the consequences of long-term ill-health. Economic heterogeneity meant differential access to resources which could buffer a shock like long-term ill-health. It meant an intensification of the politics of status maintenance – gossip, jealousy and concerns with black magic; participation in a symbolic economy predicated on conspicuous consumption and gift exchange; ritual and religious observances; the concealment of ill-health.

The greater socio-economic heterogeneity found in the ethnographic study than in the quantitative analyses may be attributed to the East London setting. According to the census, the Pakistanis in London are more socio-economically heterogeneous than most Pakistani settlements in the UK. Pakistanis are the only major ethnic group in the UK to be concentrated outside London, namely in the North-West and the Midlands, and the national statistics on Pakistanis are biased towards these larger settlements which have experienced greater unemployment and deprivation through the process of economic restructuring. Patterns of labour market circumstances in London are more varied than elsewhere, for ethnic minority groups as well as for the White majority (Simpson, Purdam et al. 2006). The economic heterogeneity among Pakistanis differentiates their experience from that of the Bangladeshis, who are not only more deprived compared to Pakistanis but also more economically homogeneous (see Modood and Berthoud 1997; Berthoud 1998; Platt 2002; Berthoud 2003; Simpson, Purdam et al. 2006). My observations of long-term sick Bangladeshis in the JRF project suggested a striking qualitative difference between Pakistanis and Bangladeshis in the intensity of conspicuous consumption.

The significance of ethnicity in the patterning of long-term ill-health and its material consequences may be seen as the exigency of a more encompassing process of material differentiation and class relations. It is inaccurate and reductive to assume that Pakistanis are inevitably located at the bottom of the British class system, as most of the sociological literature does. This study is, following Werbner, “almost unique in analysing South Asians as constituting a highly stratified community” (Werbner 1990a) (p.xiv). However, as I have criticised at various points in the thesis, to understand ethnicity solely as a proxy for structural factors is to elide questions about the processes of inclusion and exclusion through which socio-economic status is produced and reproduced in different ethnic groups; I turn to this point in due course.

9.3.2. Gender systems

In the ethnographic study, much of the talk about ‘culture’ actually concerned gender systems, in keeping with a large body of sociological work showing that women are typically the primary bearers of transnational citizenship and that expectations on women to perform ethnic identities are stronger than for men (see Yuval-Davis and Anthias 1992; Yuval-Davis and Werbner 1999; Thapan 2005). Patriarchal ideologies, legitimated by constructions of ‘Islam’ and ‘Pakistani tradition’, had a strong influence over the patterning of long-term ill-health and its consequences. Cultural constraints on female employment were undoubtedly at the root of the disproportionately high levels of worklessness found among long-term sick Pakistani women, and implicated in the higher levels of worklessness found in long-term sick Pakistani households than in other ethnic groups. The sharp normative gender division of labour constrained the coping strategies that the households could adopt. There were few examples of women who took on a breadwinner role after the onset of their husbands’ ill-health, and the experiences of those who did highlighted the difficulties for women who had often weak educational credentials and employment experience, who stood to gain little from employment in terms of pay and working conditions; they also revealed women’s ambivalence to challenging the male breadwinner ideology. However, this finding needs to be considered alongside variation in and gender roles and ideologies among Pakistanis, and strong commonalities with other ethnic groups (see Salway, Platt et al. 2007).

Patriarchal ideologies were closely related to education and the socio-economic position of the household, and to their migratory origins. There seemed to be strong patriarchal sub-cultures in the rural-origin, less educated, Kashmiri households, who aspired towards female seclusion (*purdah*) as a sign of high class. However, for the more secularised elite, *purdah* was associated with backwardness, and female employment was a sign of household modernity and affluence.

There were no simple relationships between female agency and the stereotypical dichotomies of 'traditional'-'modern' or 'religious'-'secular'. The informants drew on constructions of Pakistani 'tradition' and 'Islam' as 'officialising strategies' (Bourdieu 1977) in multifarious and purposive ways. 'Islam' was often cited to support the status quo of the gender system – but younger, educated, British-born women often cited modernist, textual interpretations of 'Islam' as grounds for claiming universal rights within a framework that queried 'Western' gender arrangements as more progressive.

This is in contrast with much of the sociological literature, which has been criticised for representations of Pakistani women that serve to “invoke emotional responses of pity by reproducing stereotypes of Asian women as passive victims of a homogenised South Asian culture that is inevitably oppressive towards them” (Ahmad 2006) (p.278). The study demonstrated continuity and change, fluidity and variation in how Pakistani men and women negotiated gendered norms. Patriarchal ideologies had power over the informants, but they impacted differentially upon them; they were contested, accommodated or asserted according to personal circumstance and structural position. Women actively negotiated the cultural values they accepted, and they did not inevitably have to lose their traditions in order to be empowered. Often, rather than challenging it, women negotiated within the 'patriarchal bargain' (Kandiyoti 1997) to pursue their own interests within households. Conforming with 'traditional' expectations and duties allowed them to draw explicitly on the interdependence of claims and obligations, power and responsibility. Self-sacrificial perseverance with everyday wifely and motherly duties in the face of ill-health therefore became a powerful lever over other family members. Women gained in power by making themselves indispensable to their households: maintaining gendered family roles, ensuring positive emotional ties with family members and reproducing at the apex of a host of loyal children. Their 'centrality' with kin was a source of power through which they could garner resources. As Ali suggests, Pakistani forms of gendered power may be expressed by:

“... a self that may accept, contradict, and even transgress the imposed construction of the mythical, yet desired 'emancipated' autonomous individual... women's assertions of their conjugal rights, situated within the construction of individualised agency, may cohabit with their desire to be modest, self-sacrificial, subservient, and humble”

(Ali 2004) (p.140)

9.3.3. Pakistani identity and networks

In the ethnographic study, the processes of inclusion and exclusion that flowed from Pakistani ethnicity – i.e. the affective claims by which the informants distinguished between ‘us’ and ‘them’ and identified a collectivity with which there was a sense of belonging – were a pervasive influence over the consequences of long-term ill-health. Experiences or fears of racialised marginalisation were important in excluding the informants’ from entitlements that were intended to mitigate the costs of ill-health, such as state healthcare, employment opportunities, welfare benefits, and support from Jobcentre Plus and other formal agencies. Pakistani ethnicity functioned as an informal code for inclusion in networks of information, favours and opportunities, affecting access to state entitlements as well as informal claims of emotional and practical support and financial exchanges. Co-ethnic networks, however, were an ambivalent resource. They privileged access to opportunities within certain economic sectors, but constrained the range of occupations that could be contemplated. They tended to secure access to low-skilled work in small businesses, but precluded access to jobs outside the ethnic economy. The informality prevailing in situations frequently entailed prejudicial terms of employment, particularly for the Freshies and the Lads, who were the most vulnerable in the labour market. They complained bitterly about exploitation at the hands of Asian (*apne*) employers in the ethnic economy. “English jobs” were sought after, offering workers a minimum of formal rights to job security in the face of long-term ill-health.

Pakistani networks of kinship-come-friendship were experienced as a double-edged presence in people’s lives. On the one hand, networks were an extremely important source of belonging and fulfilment, as demonstrated by the informants’ desire for sociability and the extensive help they were able to garner from their social ties. However, relationships were also threaded together by material need, and networks of kinship-come-friendship characterised by enmity and jealousy as well as mutual assistance. Friendship was interwoven with a pervasive discourse of mistrust (*chalakee* or craftiness). The pervasive influence of the *maashra* (society) as a source of social control had particular significance for gender roles, given the potential for rules and sanctions concerning gendered norms to develop in same-sex peer groups. The informants complained perennially about the overly close-knit, claustrophobic and oppressive nature of the *maashra* (society), particularly women and young people. Many of the younger informants aimed to move out of East London and into a more predominantly White area to escape the “rat race” and perceived backwardness of their friends and relatives. Most of the informants were, therefore,

strongly ambivalent towards Pakistani ethnicity, which offered security and support from their own networks, but which they felt also stopped them from “getting ahead”.

The ethnic diversity of East London is also likely to have affected the meanings and values attached to Pakistani ethnicity and networks in this study. Apart from the Bangladeshis, Pakistanis are among the most spatially concentrated ethnic groups in the UK (Johnston, Burgess et al. 2006). Employment rates in ethnically diverse neighbourhoods are lower for all most ethnic groups (Simpson, Purdam et al. 2006). The mistrust about financial trickery that pervaded the social networks is likely to reflect the higher levels of material need that knitted relationships together (Brannen and Wilson 1987). The tensions and contradictions expressed towards the *maashra* are also likely to stem from the high concentration of Pakistani population in East London. Ahmad has criticised sociological research on British Asians for its tendency to focus on localities with a high concentration of Asian population, which give a misleading impression of people living in unmixed, White localities and overly tribalises how ethnic communities are represented (Ahmad 2003). Social networks must be recognised to impact upon people’s lives in varying ways, in accordance with the ethnic diversity of the locality, social class, migratory origins and migration histories.

The economic polarisation of East London is also likely to have affected the meanings and values attached to Pakistani ethnicity and networks. The social meanings of Pakistani ethnicity varied noticeably in accordance with social class; the power of social categories was determined by their fluctuating relationship to other categories (Bourdieu 1984). For those in the precarious underclass, Pakistani networks were a key resource, and the boundaries of status were drawn around the possession of Pakistani ethnic capital; whereas many of the secularised elite were re-working the meanings of Pakistani ethnicity and developing ways to distinguish themselves from working class Pakistanis. As Ramji observes:

“...[the upwardly mobile] cohort were concerned with gaining access to White middle class spaces and distinction from the ‘Pakistani’ ethnicity the working class men were so keen to cultivate... this entailed some collusion and co-operation in maintaining types of ‘lower’ cultural capital, and working with the stereotypes of the religious fanatic and backward Pakistani to measure their difference against”.

(Ramji 2005) (p.11)

9.4. Practical recommendations

This thesis was not a systematic study of the state or its services. Nonetheless, we were able to view the state from the perspective of the household, in its parochial manifestations. This ‘state in society’ approach allows us to grasp the cohesiveness of the image of the state as well as the contradictory and incoherent nature of some of its practices (Migdal 2001). From this study, it is clear that there were a number of instances in which statutory services were being delivered to the informants sub-optimally, or worse, where state intervention was actually making their lives more difficult. This final section therefore brings together some of the findings that are relevant to current health and welfare concerns in the UK.

9.4.1. Managing long-term ill-health

The stated imperative of health policy towards long-term condition management is to improve quality of life and reduce the burden of caring for long-term conditions to the NHS. The latest directive, *Raising the Profile of Long-term Condition Care*, promotes a three-part hierarchical structure for people with long-term ill-health. For those with multiple problems and a high propensity to use primary and the more costly secondary care, a strategy of ‘case management’ is proposed via community matrons. For those with single, serious conditions a secondary strategy of ‘disease management’ is proposed via improved primary care. For the remaining 70-80% of individuals living with chronic conditions a programme of self-care or self-management is proposed (DOH 2008). Although self-management programmes like the Expert Patient Programme have so far received a limited amount of investment and attention, government publications stress their significance to strategic thinking on healthcare delivery. Taylor and Bury have called this a ‘care transition’ (Taylor and Bury 2007).

Equity is a particularly important issue in ‘care transition’ policies, as they have the potential to marginalise further the people who are least able to help themselves. In this study, many of the informants had poor experiences of healthcare. Health practitioners had a large and potentially negative influence over the informants’ subjective responses to ill-health and their health management. Differences of ethnicity and class status were important barriers between the informants and health practitioners, suggesting that providing more ethnic minority staff may not be a simple solution for the NHS (Ali, Atkin et al. 2006). Poor experiences of NHS healthcare forced a number of the informants into the private sector despite being ill-able to afford the fees for private healthcare. It is therefore key that frontline staff should be trained to work with diverse

service users in a culturally competent manner. However, given the variation among the informants, particularly in accordance with class, gender and generation, it is important for practitioners to be culturally competent without falling back on stereotyping assumptions (Atkin and Chatoo 2007; Kai, Beavan et al. 2007).

Informal networks were important as sources of support in dealing with long-term ill-health and a productive route for disseminating information. However, many of the informants eschewed informal counselling and group-based peer support. The focus on self-management through participation in group-based interventions may therefore exclude individuals who are unwilling to identify themselves publicly as sick. Moreover, coping responses were shaped by socio-cultural constructions of ill-health, gendered normative ideals about how to respond to it, and stigma. For people with mental illness, the prospect of joining a support group could be particularly threatening to individual identities. In practical terms, there is therefore a need for ensuring more diverse modes of support to people living with long-term health conditions. Many of the informants had low self-efficacy in “taking control of” their health conditions as a result of other, competing concerns such as financial hardship or problems connected to their status as new migrants. The relevance of self-management programmes to people in such circumstances is questionable. Indeed, attendance at self-management groups and support groups organised around specific illnesses appears to be biased towards White middle-class people. To date, deprived and minority ethnic groups have been under-represented in the Expert Patient Programme and other self-management schemes (Barlow, Turner et al. 2000; Buszewicz, Rait et al. 2006; Kennedy, Reeves et al. 2007). However, there are some examples of good practice, which broadly highlight the importance of recruiting lay tutors from minority ethnic groups (see Griffiths, Motlib et al. 2005).

9.4.2. Employment

Welfare policy views employment as the main route out of poverty, and recently there has been increased attention to the economic inactivity of individuals with long-term conditions (DWP 2006). Welfare-to-work programmes appear to have had some success in supporting long-term sick people into employment (Bambra, Whitehead et al. 2005), although supporting people with severe mental ill health appears to be more challenging (Burns, Catty et al. 2007). Despite these apparent successes, however, there is no evidence on which to evaluate whether welfare-to-work initiatives have reached equally across ethnic groups. In this study, many of the informants had reservations about Jobcentre Plus and other formal agencies intended to support individuals into

employment; and for some, these reservations related to racialised processes of exclusion. Diverse modes of outreach are therefore needed to ensure that employment support is accessible to marginalised groups. Pathways to Work have recently piloted a scheme placing Jobcentre Plus advisers in GP surgeries in England (Elliott 2007), which seems to be a sensible strategy for improving access to long-term sick people

It was clear from this study that employment was not a priority for all of the informants, particularly elder people and women, who often preferred inactivity – although it is important to recognise that preferences are structured by socio-cultural and economic contexts. Job-search support needs to be tailored to individual needs, although again, it is important for practitioners not to fall back on stereotyping assumptions. Practitioners need to consider the benefits of work alongside its potentially negative health impacts, as juggling work alongside complex health management needs and caring responsibilities may have a detrimental impact on peoples' overall wellbeing. It is important to recognise the economic value of activities outside employment that are equally important for household welfare, and recognise the needs of carers.

Many of the informants faced a return to low paid work that offered little financial reward over claiming benefits. Similarly, many of the long-term sick informants returned to temporary or precarious employment that they were unable to maintain, and then faced an arduous battle in re-claiming their benefits entitlements. The informal economy provided income to supplement the low levels of benefits, but under conditions that could be quite exploitative and prejudicial to the employees (Katungi, Neale et al. 2006). Increased attention needs to be paid to training, job retention and the quality of employment, which have been shown to be more important for job retention in the longer term (Lindsay, McQuaid et al. 2007).

The proprietors of small or struggling businesses were in a particularly precarious position after the onset of long-term ill-health, standing to lose their own personal assets, and with scant entitlements to job protection, sick leave and sick pay. There were also tensions between employers' needs for a reliable workforce and the unpredictable and disruptive nature of long-term ill health, and the capacity – and incentives – for employers to offer flexible opportunities to long-term sick people require practical and legislative support. The combination of obstacles to employment resulting from ill health, low skills and racism resulted in particularly low employment chances for the Pakistani informants, and low pay for those who were in work. In the absence of state support to address these underlying problems, welfare-to-work policies are unfair, requiring the people least able to do so to pull themselves up on the strength of their own

resources. Policy makers need to appreciate that the capacity of long-term sick to participate in employment is strongly limited by the job opportunities presented by the local labour market (Fothergill and Wilson 2007).

9.4.3. Welfare benefits

Current welfare policy aims to move long-term sick people off benefits and into work (DWP 2006). Sickness-related benefits are an essential, if not necessarily fully adequate, contribution towards maintaining standards of living. However, the take-up of benefits among eligible people is low. Levels of work-restricting ill health among claimants of unemployment-related benefits are high, implying that significant numbers of people do not take up ill-health related benefits that could improve their standard of living when they develop a health condition (Bacon 2002). Importantly, the quantitative analysis here showed that the receipt of sickness-related benefits seems to be particularly low for minority ethnic groups, and particularly for Pakistanis and Bangladeshis. Access to benefits among long-term sick people appears to be limited by a lack of knowledge, which may be compounded by English language difficulties as well as marginalisation from welfare services due to actual or perceived racial discrimination (Barnard and Pettigrew 2003). Aversion to benefits dependency needs to be countered by an entitlement-based approach and the culture of stigmatising sickness claimants as undeserving needs to be challenged.

The strict assessment procedures for benefits were frequently experienced as complex, unpredictable and stressful, despite evidence elsewhere suggesting that levels of fraud are low (Hedges and Sykes 2001). Health status assessments (such as GP certification or Personal Capacities Assessment) were found to be unfair and inappropriate, particularly in relation to mental illness. Since the time of fieldwork, responding to criticisms following the consultation for the Welfare Reform Green Paper, the Personal Capacities Assessment has been revised to take greater account of the needs of people with mental ill health. Many of the informants were accessing benefits via informal ties, despite evidence that specialist support is needed for applications or appeals to be successful. Specialist support needs to be expanded. In England, however, the number of GP surgeries offering benefits advice has declined since 2005 (Elliott 2007). Although entitlement criteria are complex, it is important that a wide range of practitioners should be able to provide advice and support to claiming relevant benefits. The reliance on informal ties suggests that there is a need to diversify modes of outreach to ensure that benefits support is accessible to more marginalised groups.

The potential for welfare benefits to mitigate the economic stress brought on by long-term ill-health was limited by the misrecognition of systematic differences between the realities of Pakistani family life and the normative White ideals that inform the 'benefit unit' model of the family, particularly concerning family size. The non-individualised delivery of benefits through the 'benefits unit' also hindered women's control over finances and consequently, their gendered power within marriage (see Lewis and Bennett 2003). Transnationalism also hindered access to benefits. The restriction of the right to sponsor a spouse to those who were in work and not claiming benefits was extremely prejudicial to long-term sick and unemployed individuals, forcing them to abstain from welfare benefits and deepening their financial poverty whilst their cases were still unresolved, and contravening their right to a family life as guaranteed by the European Convention on Human Rights. State practices, as Das and Poole suggest, are 'illegible' (Das and Poole 2004); the state speaks with multiple voices, and makes contradictory demands of its citizens.

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Appendix 1: Descriptive statistics for variables used in individual-level analysis: men

	White British	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Mixed/ other
<i>Age group</i>								
18-29	19%	28%	40%	40%	20%	30%	40%	26%
30-44	36%	38%	35%	44%	51%	51%	36%	41%
45 plus	45%	35%	25%	16%	29%	19%	25%	33%
<i>Health factors</i>								
<i>Long-term ill health</i>								
No	74%	80%	75%	74%	75%	85%	89%	79%
Yes	26%	20%	25%	26%	25%	15%	11%	21%
<i>Activity limitations</i>								
No	84%	87%	82%	83%	86%	91%	96%	87%
Yes	16%	13%	18%	17%	14%	9%	4%	13%
<i>Number of health conditions</i>								
0	74%	80%	75%	75%	75%	85%	89%	79%
1	14%	10%	11%	12%	14%	10%	8%	11%
2	5%	4%	6%	6%	5%	3%	2%	5%
3+	7%	5%	8%	7%	6%	3%	1%	6%
<i>Economic activity</i>								
In paid work	83%	80%	67%	61%	73%	69%	71%	77%
Unemployed	4%	5%	9%	13%	11%	10%	4%	6%
Inactive	14%	16%	24%	25%	16%	21%	26%	17%
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas	27%	34%	19%	14%	17%	35%	40%	27%
Level 3 + apprenticeships	30%	17%	14%	8%	26%	16%	15%	18%
Level 2	11%	8%	9%	8%	14%	9%	5%	7%
Level 1	12%	7%	9%	9%	16%	5%	4%	6%
Other	8%	20%	23%	23%	11%	28%	23%	28%
None	12%	15%	26%	37%	15%	7%	14%	13%
<i>NSSEC</i>								
Managerial & professional	39%	39%	19%	16%	28%	28%	39%	40%
Intermediate	17%	17%	24%	12%	15%	11%	15%	15%
Routine & manual	36%	29%	34%	43%	40%	32%	16%	30%
Neverworked or 1-t unemployed	2%	2%	6%	8%	7%	6%	3%	4%
Full-time student	3%	9%	11%	17%	5%	22%	25%	7%
Missing	4%	4%	6%	4%	5%	3%	2%	4%
<i>Housing</i>								
Owner occupied	80%	83%	80%	42%	59%	33%	59%	57%
Rented privately	8%	11%	9%	12%	9%	25%	31%	26%
Social housing	12%	6%	11%	46%	31%	41%	10%	16%
<i>Family characteristics</i>								
<i>Married or cohabiting</i>								
Yes	70%	70%	70%	66%	50%	53%	54%	65%
No	30%	30%	30%	34%	50%	47%	46%	35%
<i>Child(ren) below 5 years in family</i>								
No	87%	82%	68%	62%	84%	76%	88%	83%
Yes	13%	18%	32%	38%	16%	24%	12%	17%
<i>Welfare benefits</i>								
<i>Disability Living Allowance</i>								
No	97%	98%	97%	98%	97%	98%	99%	98%
Yes	3%	2%	3%	2%	3%	2%	1%	2%
<i>Income Support</i>								
No	96%	97%	91%	89%	93%	96%	99%	95%
Yes	4%	3%	9%	11%	7%	4%	1%	5%
<i>Unemployment benefits & NI credits</i>								
No	98%	98%	95%	91%	92%	94%	99%	97%
Yes	2%	2%	5%	9%	8%	6%	1%	3%
TOTAL	271,388	5,352	3,233	1,255	2,454	2,115	1,058	17,362

Data source: LFS 2002-5 (pooled quarters).

Appendix 2: Descriptive statistics for variables used in individual-level analysis: women

	White British	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Mixed/ other
<i>Age group</i>								
18-29	21%	29%	40%	47%	23%	31%	36%	28%
30-44	41%	43%	39%	36%	53%	53%	37%	45%
45 plus	38%	28%	21%	17%	24%	16%	27%	28%
<i>Health factors</i>								
<i>Long-term ill health</i>								
No	75%	82%	75%	73%	74%	82%	89%	80%
Yes	25%	18%	25%	27%	26%	18%	11%	20%
<i>Activity limitations</i>								
No	84%	87%	81%	81%	84%	90%	95%	88%
Yes	16%	13%	19%	19%	16%	10%	5%	12%
<i>Number of health conditions</i>								
0	75%	82%	75%	73%	74%	82%	89%	80%
1	12%	9%	10%	12%	14%	11%	7%	10%
2	5%	4%	5%	9%	6%	4%	2%	4%
3+	8%	5%	10%	6%	6%	3%	1%	6%
<i>Economic activity</i>								
In paid work	74%	65%	27%	22%	69%	52%	58%	65%
Unemployed	3%	5%	5%	4%	6%	7%	4%	4%
Inactive	24%	30%	68%	75%	25%	41%	38%	31%
<i>Socio-economic characteristics</i>								
<i>Education</i>								
Degree + higher level diplomas	26%	27%	14%	8%	30%	28%	37%	30%
Level 3 + apprenticeships	16%	13%	10%	8%	15%	11%	11%	10%
Level 2	18%	12%	13%	8%	19%	11%	6%	8%
Level 1	19%	9%	11%	12%	19%	7%	5%	8%
Other	5%	20%	17%	17%	7%	27%	25%	30%
None	15%	19%	35%	47%	10%	16%	15%	13%
<i>NSSEC</i>								
Managerial & professional	32%	28%	11%	8%	34%	23%	29%	35%
Intermediate	21%	20%	9%	6%	20%	11%	18%	17%
Routine & manual	32%	26%	17%	18%	26%	27%	19%	24%
Neverworked or l-t unemployed	2%	12%	44%	58%	5%	20%	8%	9%
Full-time student	4%	8%	9%	6%	8%	16%	21%	7%
Missing	8%	7%	9%	4%	7%	3%	5%	7%
<i>Housing</i>								
Owner occupied	77%	82%	76%	40%	50%	29%	63%	58%
Rented privately	8%	10%	10%	6%	9%	21%	28%	24%
Social housing	16%	8%	14%	53%	41%	51%	9%	18%
<i>Family characteristics</i>								
<i>Married or cohabiting</i>								
Yes	68%	69%	67%	72%	35%	37%	61%	65%
No	32%	31%	33%	28%	65%	63%	39%	35%
<i>Child(ren) below 5 years in family</i>								
No	84%	80%	66%	58%	78%	70%	85%	81%
Yes	16%	20%	34%	42%	22%	30%	15%	19%
<i>Welfare benefits</i>								
<i>Disability Living Allowance</i>								
No	96%	98%	96%	97%	96%	98%	100%	97%
Yes	4%	2%	4%	3%	4%	2%	0%	3%
<i>Income Support</i>								
No	93%	96%	88%	88%	83%	79%	97%	93%
Yes	7%	4%	12%	12%	17%	21%	3%	7%
<i>Unemployment benefits & NI credits</i>								
No	99%	99%	98%	98%	98%	97%	99%	99%
Yes	1%	1%	2%	2%	2%	3%	1%	1%
TOTAL	266,231	5,452	3,424	1,264	2,937	2,890	1,222	19,490

Data source: LFS 2002-5 (pooled quarters).

Appendix 3: Descriptive statistics for variables used in household-level analysis

	White British	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Chinese	Mixed/ other
<i>Health of adults in the household</i>								
<i>One or more person(s) with long-term ill-health</i>								
No	57%	61%	51%	55%	63%	74%	78%	63%
Yes	43%	39%	49%	45%	37%	26%	22%	37%
<i>One or more person(s) with activity limitations</i>								
No	72%	71%	61%	65%	76%	83%	88%	75%
Yes	28%	29%	39%	35%	24%	17%	12%	25%
<i>Household worklessness</i>								
No	88%	90%	74%	68%	79%	67%	80%	82%
Yes	12%	10%	26%	32%	21%	33%	20%	18%
<i>Household characteristics</i>								
<i>Number of people in household</i>								
2	41%	24%	14%	10%	38%	28%	32%	37%
3	25%	23%	16%	15%	30%	27%	28%	25%
4	24%	29%	23%	24%	21%	23%	23%	24%
5+	10%	24%	47%	51%	11%	22%	17%	15%
<i>Household type</i>								
Couple with dependent children	38%	46%	57%	61%	28%	32%	32%	40%
Couple without children	31%	16%	8%	6%	12%	8%	19%	25%
Couple with non-dependent children	9%	9%	3%	2%	4%	1%	8%	7%
Lone parent with dependent children	12%	7%	12%	12%	41%	36%	9%	14%
Lone parent with non-dependent children	3%	3%	1%	1%	5%	4%	3%	3%
Complex (multiple family) household	6%	19%	19%	19%	9%	19%	30%	11%
<i>Household containing elderly person(s)</i>								
No	93%	90%	94%	93%	97%	98%	96%	94%
Yes	7%	10%	6%	7%	3%	2%	4%	6%
<i>Household containing child(ren) under 15</i>								
No	52%	44%	24%	16%	31%	29%	62%	48%
Yes	48%	56%	76%	84%	69%	71%	38%	52%
<i>Socio-economic factors</i>								
<i>Education</i>								
Degree + higher level diplomas	28%	33%	18%	10%	24%	33%	39%	28%
Level 3 + apprenticeships	26%	12%	10%	4%	19%	10%	9%	20%
Level 2	12%	6%	7%	4%	17%	9%	5%	9%
Level 1 [equivalent to GCSE]	13%	7%	8%	7%	19%	5%	5%	7%
Other	13%	18%	33%	52%	12%	16%	17%	17%
No qualifications	7%	24%	25%	23%	9%	28%	27%	19%
<i>Housing</i>								
Owner occupied	77%	79%	72%	36%	50%	28%	58%	64%
Rented privately	8%	13%	13%	9%	8%	22%	32%	19%
Social housing	15%	7%	15%	55%	43%	50%	10%	17%
TOTAL	160,473	3,018	1,796	690	1,802	1,736	622	17,394

Note: Households were restricted to working-age multiple-member households, hence the percentages here differ from Tables 3.2. and 3.4. in Chapter 3 which are have working-age households, including single person households, as a denominator. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person. Education was assigned to the household on the basis of the qualifications of the household reference person.

Data source: HLFS 2002-4.

Appendix 4: Estimates from logistic regression indicating the effects of relevant factors on the presence of adult(s) with long-term ill-health or activity limitations in households

	Long-term ill-health				Activity limitations			
	Model 1		Model 2		Model 1		Model 2	
	OR	P-value	OR	P-value	OR	P-value	OR	P-value
<i>Ethnicity</i>								
White British	1		1		1		1	
Indian	0.82	<0.001	0.78	<0.001	1.01	0.73	1.00	0.912
Pakistani	1.29	<0.001	1.27	<0.001	1.63	<0.001	1.66	<0.001
Bangladeshi	1.14	0.083	1.11	0.18	1.41	<0.001	1.43	<0.001
Black Caribbean	0.80	<0.001	0.90	0.014	0.81	<0.001	0.88	0.007
Black African	0.50	<0.001	0.55	<0.001	0.53	<0.001	0.58	<0.001
Chinese	0.36	<0.001	0.34	<0.001	0.32	<0.001	0.31	<0.001
Mixed/other	0.82	<0.001	0.83	<0.001	0.89	<0.001	0.90	<0.001
<i>Household characteristics</i>								
<i>Number of people in household</i>			1.13	<0.001			1.13	<0.001
<i>Household composition</i>								
Single person			1				1	
Couple with dependent children			0.66	<0.001			0.55	<0.001
Couple without children			1.27	<0.001			1.11	<0.001
Couple with non-dependent children			1.74	<0.001			1.39	<0.001
Lone parent with dependent children			0.61	<0.001			0.59	<0.001
Lone parent with non-dependent children			1.45	<0.001			1.33	<0.001
Complex (multiple-family) household			0.96	0.105			0.82	<0.001
Quarterly dummies	1.01	0.005	1.01	0.006	1.017033	<0.001	1.02	<0.001
Pseudo R2		0.0021		0.0177		0.002		0.0149
Number of observations		234240		234240		234240		234240

Note: Households were restricted to working-age households. Ethnic group was assigned to the household on the basis of the ethnicity of the household reference person. Education was assigned to the household on the basis of the qualifications of the household reference person.

Data source: HLFS 2002-4.

Appendix 5: Glossary of Urdu and Punjabi words

<i>Aakhrat</i>	Judgement day, afterlife
<i>Aana-jana</i>	Lit. 'coming and going', socialising
<i>Aitbaar</i>	Trust
<i>Apna/apne</i>	One's own
<i>Apni marzi karna</i>	To do as one wants, wishes
<i>Asmaish</i>	Test, examination
<i>Awara, awargi, awaragardi</i>	Loose, free
<i>Baatoonee</i>	Chatterbox
<i>Babas</i>	Elder men, honorific name
<i>Baddua</i>	Curse
<i>Bahr ni cheez</i>	Lit. 'thing from outside', <i>djinn</i>
<i>Baji</i>	Elder sister, honorific name
<i>Barhe</i>	Elders
<i>Berozghar</i>	Unemployed
<i>Besharom</i>	Without shame
<i>Bibi ka ghulam</i>	Lit. 'wife's servant', weak man
<i>Bimaar</i>	Ill, sick
<i>Biradari</i>	Extended family, patrilineage, clan, relatives
<i>Bhaijan</i>	Elder brother, honorific name
<i>Chalakee</i>	Craftiness, guile
<i>Chiri-chiri</i>	Irritable
<i>Chuglee</i>	Gossip, bitching
<i>Dal</i>	Lentils
<i>Dari</i>	Beard, may be sign of religiosity
<i>Daawat</i>	Lit. 'invitation', entertaining guests at home
<i>Dekhbal karna</i>	To look after
<i>Djinn</i>	Spirit of fire, according to Quran
<i>Duniyadari</i>	Materialism, worldliness
<i>Eid</i>	Islamic festivals
<i>Farz</i>	Obligation, duty
<i>Freshie</i>	New (labour) migrant
<i>Ghair</i>	Outsider, not one of 'us'
<i>Gharwale</i>	Household members, family
<i>Gheebat</i>	Backbiting

<i>Ghuzara karna</i>	To get by, to make do, to make ends meet
<i>Gora/gori</i>	White, English
<i>Hakeem</i>	Practitioner of Islamic medicine
<i>Halka kam</i>	Light work
<i>Hatta-katta</i>	Fit, healthy
<i>Hera-pheri</i>	Trickery, fraud
<i>Hikmet</i>	Islamic medicine
<i>Hukoomat</i>	Government
<i>Ikher ki</i>	Lit. 'from here', young British-born woman
<i>Ikathe</i>	Togetherness, interdependence
<i>Imam</i>	Priest in mosque
<i>Imtehan</i>	Test, examination
<i>Izzat</i>	Respect, honour, status
<i>Izzatdar log</i>	Respectable, honourable, decent people
<i>Izzatdar zindegi</i>	Decent life
<i>Jadhoo</i>	Black magic
<i>Jahil</i>	Uncouth, uneducated
<i>Jannat</i>	Heaven
<i>Jawaan</i>	Young, grown-up
<i>Jilbab</i>	Arab dress covering body from neck to feet
<i>Kakas</i>	Lit. 'son' or 'boy', children of the <i>babas</i>
<i>Kameti</i>	Committee, rotating credit association
<i>Kamzoor</i>	Weak, thin, frail, vulnerable
<i>Khayal karna</i>	To look after
<i>Khidmat</i>	Lit. 'service', care, attendance
<i>Koti</i>	Mansion, independent house
<i>Kismat</i>	Fate, destiny, luck
<i>Lads</i>	Young British-born men
<i>Lafunga</i>	Good-for-nothing
<i>Lambe arse ki bimaaree</i>	Long-term ill-health
<i>Laperwah</i>	Irresponsible, careless
<i>Lena-dena</i>	Giving-taking, ritual gift exchange system
<i>Maande</i>	Weak, thin, frail, vulnerable
<i>Maashra</i>	Society
<i>Mahaul</i>	Environment, social climate
<i>Majboori</i>	Lit. 'compulsion', 'necessity', financial poverty
<i>Mangetar</i>	Lit. 'fiancé/fiancée', marriage migrant

<i>Mangni</i>	Engagement, betrothal
<i>Mareez</i>	Patient, sick person
<i>Mayoosi</i>	Despair, depression
<i>Mehndi</i>	Henna
<i>Milad-un-Nabee</i>	Islamic festival celebrating the birth of the prophet
<i>Milna-julna</i>	Socialising
<i>Namaz</i>	Islamic prayer
<i>Nashukree</i>	Ingratitude
<i>Nazar</i>	Evil eye
<i>Nikaah</i>	Islamic marriage vows
<i>Paagal</i>	Mad
<i>Pareshan</i>	Lit. 'worried', depressed, unhappy, restless
<i>Peer</i>	Saint
<i>Piche ghar</i>	Lit. 'back home', Pakistan
<i>Purdah</i>	Lit. 'veil', female seclusion
<i>Rishta</i>	Arrangement of a marriage, relationship
<i>Rishtedar</i>	Relative
<i>Roti</i>	Lit. 'bread', basic food
<i>Sabar</i>	Steadfastness, patience
<i>Sawab</i>	Religious merit
<i>Shaadi</i>	Wedding
<i>Shalwar-kameez</i>	'Traditional' Pakistani dress, trousers and shirt
<i>Sharif</i>	Respectable, honourable, decent, holy
<i>Sharom</i>	Shame
<i>Shaunk</i>	Pleasure, desire
<i>Sooka</i>	Dry, thin
<i>Takleef</i>	Suffering
<i>Tandroost</i>	Fit, healthy
<i>Topi</i>	Cap, often a sign of religiosity
<i>Udher ki</i>	Lit. 'from there', young Pakistan-born woman
<i>Ulad</i>	Children, offspring
<i>Valda</i>	Lit. 'mother', older Pakistan-born women
<i>Vartan-bhanji</i>	Gifts exchanged at life-cycle marking events
<i>Yaqeen</i>	Belief, faith
<i>Zam zam pani</i>	Holy water from Mecca Sharif
<i>Zanmureed</i>	Lit. 'follower of women', weak man
<i>Zimedaree</i>	Responsibility