

**PERFORMING *ALLAH'S* WORK:  
EXPERIENCES OF MUSLIM  
FAMILY CARERS IN BRITAIN**

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## **ABSTRACT**

This thesis explores how Muslim family carers of chronically ill or disabled family members in Britain perceive, perform and negotiate their caring role. Drawing on data collected from forty-three semi-structured interviews, this thesis shows that although Muslim family carers are not a homogenous group; perceptions, performances and negotiations of care within the family are often mediated through a Muslim religious lens. This manifests itself in three predominant ways explored in this thesis. Firstly, Muslim religious beliefs act as a 'sacred canopy' through which carers draw comfort and spiritual meaning for both their caring role and the illness and disability of the cared for relative. Secondly, certain state services are deemed as particularly problematic for upholding Muslim religious identities. Whilst health services are positively received, social services often are deemed as 'dangerous' and potentially threatening to family honour (*izzat*). This is particularly pertinent for carers of females with learning disabilities. Thirdly, Muslim religious and cultural beliefs maintain traditional gendered perceptions of caregiving within the family, often with very little support from outside organisations. This thesis also argues that Muslim carer support organisations use interesting and innovative methods of engaging Muslim family carers as a form of 'bridging social capital' to health and social services.

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# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 INTRODUCTION**

Muslims in Britain have been the focus of profuse scholarly and media attention over the past ten to fifteen years (Gilliat-Ray, 2010). Many aspects of Muslim life including religious fundamentalism (Bruce, 2000; Ruthven, 2004), education (e.g. Fetzer and Soper, 2005; Anwar, 2005; Lewis, 1994), gender (e.g. Basit, 1997; Brown, 2006; Ramji, 2007; Williams and Vashi, 2007) and health (e.g. Hasnain *et al.*, 2008; Horne *et al.*, 2004; Sheikh and Gatrad, 2000) have been analysed, scrutinised and researched. This is due in part to the tragic terrorist attacks of 9/11 and 7/7 (Laird *et al.*, 2007), which substantially accounts for the profoundly negative spotlight placed on Muslim communities in Britain (Bagguley and Hussain, 2005; Gilliat-Ray, 2010).

In parallel with this, the last twenty years has seen an increased emphasis on care and informal caregiving from policy makers, professionals and academics (Phillips, 2007: 2). Meanwhile, age (e.g. Becker and Aldridge, 2003; Da Roit, 2007; Wegner, 2001), gender (e.g. Dalley, 1996; Twigg and Atkin, 1994), ethnicity (e.g. Adamson and Donavon, 2005; Atkin, *et al.*, 2002; Atkin and Jones, 2008; Neufeld *et al.*, 2002) and class (e.g. Gallagher-Thompson and DeVries, 1994;

Merrill, 1997) have been explored in relation to how care is experienced by families, professionals and health service providers.

It is worthy to note, therefore, that within these two strands of sociological thought, very little attention has married these areas of interest to specifically explore the experiences of *Muslim carers*. This is not to suggest that researchers have not included Muslim carers in their studies, however, studies exploring the conjoining of Muslims and carers are relatively few. However, findings from these investigations have produced some interesting suggestions about the potentially unique experiences of caring as a Muslim. For example, Atkin and Ahmed (2000) studied parents of children with sickle cell disorder or thalassaemia. Their respondents solely comprised of South Asian parents, a subset of which were Muslim. Religious belief was a salient factor in their findings, especially for the Muslim carers in the study. For these respondents, *Allah* was credited with omniscient control over the illness and parents understood their caring role as a duty from God. Similarly, Ahmed and Rees Jones (2008), in their study on Bangladeshi carers in London, found that respondents overwhelmingly perceived their caring role as an Islamic duty, which potentially constrained access to formal services outside of the family, due to fears that it indicated a failure to cope. Whilst these studies provide an invaluable addition to knowledge about the diverse experiences of care for Britain's South Asian communities, it cannot be assumed that Muslim

family carers are necessarily sufficiently represented by conclusions drawn from these studies.

The 2001 National Census provides some potentially interesting data about British Muslims, and more specifically, about informal caring within Muslim communities. According to the Census, Muslim communities in Britain tend to be predominantly from South Asian origin, particularly Pakistan (42.5%), Bangladesh (16.8%) and India (8.5%) (ONS<sup>1</sup>, 2001). Carers from Pakistani and Bangladeshi origin reported undertaking a substantially higher amount of care than other ethnic groups. Furthermore, women from these ethnic communities were twice as likely as men to provide informal care (Young, *et al.*, 2005). When we combine these findings with reports from the Census that Muslims are more likely than any other religious community to suffer from a long-term disability (24% of Muslim women and 21% of Muslim men), we begin to notice an interesting gap in knowledge about caring within Muslim communities.

As such, this study aims to specifically explore the lives of Muslim family carers, by using semi-structured interviews to gather information from respondents who voluntarily agree to take part in the research. It is primarily concerned with answering the following overall thesis question: 'How do Muslim family carers of chronically ill or disabled family members perceive, perform and negotiate their caring role?' To

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<sup>1</sup> The Office for National Statistics is denoted here as 'ONS'.

fully explore this question, three research questions are presented and examined below:

*1. In what ways do Muslim family carers of chronically ill or disabled relatives perceive their experiences to be informed by religious beliefs?*

The existing body of literature on the role of faith and spirituality for family carers tends to predominantly focus on Christian denominations (Bennett *et al.* 1995; Dollahite, 2003; Hatton *et al.* 2004; Poston and Turnbull, 2003; Skinner *et al.* 2001; Trelour, 2002). However, these studies suggest that religion tends to play an important role for the carers in their studies. These assertions may be combined with the suggestions made by scholars documenting the role of Islam within perceptions about health, illness and disability, who explain that a Muslim faith was often of significance for the respondents in their study (Ahmed and Rees Jones, 2008; Atkin and Ahmed, 2000; Atkin *et al.*, 2002). This exposes an interesting gap in knowledge about the specific role of faith and spirituality for Muslim family carers, which my research seeks to address.

*2. How do Muslim family carers of chronically ill or disabled relatives perceive, experience and negotiate health and social services?*

This question is constructed in response to much existing literature, which has tended to suggest that access to health and social services is

particularly difficult for carers from South Asian communities (Atkin, *et al.* 2002; Hussain, 2005; Katbamna, *et al.*, 2004; Loudon, 2003). Here, language barriers and religiously and culturally insensitive facilities have been cited as reasons for low uptake of services for this demographic of carers. Therefore, this question aims to explore how access to health and social services are perceived, experienced and negotiated by Muslim family carers.

*3. How do Muslim family carers of chronically ill or disabled relatives experience and utilise both formal and informal support networks?*

As discussed above, the aspect of gender found in the 2001 National Census pertaining to carers of Pakistani and Bangladeshi descent (Young *et al.*, 2005) suggests that there may be factors specific to Muslim communities that influence the gendered experience of care. As such, this question aims to examine the extent to which the performance of care within Muslim families is undertaken as a 'feminine' task. Further to this, the question aims to explore how support networks are formulated and negotiated by those who assume the responsibility of care for a family member. This includes an exploration of the formal support networks that a carer accesses such as carer support groups.

This thesis aims to give an account of how the research project was initially conceived, planned, and carried out. It then goes on to discuss relevant literature within these fields. It also explores methodological

issues for answering the research questions. Having done this, it then sets out to analyse and interrogate data collected from twenty-eight semi-structured interviews with Muslim family carers, and a further fifteen semi-structured interviews with professionals, whose business it is to support Muslim family carers. From the data emerged a number of themes pertaining to the research questions. These themes form the basis of three 'data chapters' briefly introduced below. The main conclusions from these chapters are analysed in a final chapter at the end of this thesis.

In response to the aims of this thesis, I wish to begin by presenting how I initially became interested in conducting this research project. The chapter then discusses a small research project conducted during the summer of 2005 with prominent Muslim community group leaders and how the experience shaped how I then went on to undertake my PhD research. The chapter ends by outlining the main points of each chapter.

## **1.2 THE EMERGENCE OF A RESEARCH IDEA: CHALLENGING PRECONCEPTIONS AND ASSUMPTIONS**

On reflection about the research process, I realise that my initial interest in Muslim family carers was born out of some specific preconceptions about this particular group of people. Perhaps predictably, my findings were much more complex than I had originally anticipated. I present my



preconceptions here as a starting point from which the thesis develops and grows, as my preconceptions were replaced by both my observations whilst in the field, and in response to the findings in the data I collected.

My initial interest in Muslim affairs developed in 2004 at a time of accentuated political and social unease. The previous year had seen Britain complicit in the invasion of Iraq, against the wishes of many of its citizens who questioned the justifications and ethics of the war. This invasion sparked the popular political commentator Michael Moore to release his hard-hitting film documentary *Fahrenheit 9/11*, which publicised some of the first pictures of the devastation caused by the war in Iraq. Documenting the civilian casualties of war made for difficult viewing. Shortly afterwards, people started asking question about why so few news reports covered the civilian voices of the Iraqi people (Lewis, 2004). This was compounded by the seemingly homogenising discourses surrounding both the 9/11 terrorist attacks, and the ensuing wars in Iraq and Afghanistan, which closely associated the terms 'Muslim' and 'Islamic' with the terms 'extremist', 'fundamentalist' and 'terrorist' (Ahmed, 2003). In tandem with this, daily reports about racist attacks on British Muslim citizens intensified tensions and highlighted the relevance of the term 'Islamophobia'<sup>2</sup> in contemporary British Society (e.g. Muir, 2004; Wintour, 2004, see also Aldridge, 2007). Combining all these factors painted a worrying picture for global Muslim

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<sup>2</sup> The term 'Islamophobia' was coined by The Runnymede Trust (1997), which attempted to depict a growing hatred of Islam and its followers.

communities, something I found myself becoming increasingly interested in.

During this time I was embarking on a Master's degree in Research Methods (Sociology). The course was cross faculty and involved collaborations with a number of disciplines, including Nursing. As a result, reading material was often based on the sociology of health and illness, which began to interest me. Of particular significance to me was Isobel Bowler's (1994) ethnographic study of Midwives' stereotypes of South Asian patients in a maternity ward, which exposed some shocking racist stereotypes about South Asian women in a healthcare setting. Further exposure to this body of literature led me to more recent studies such as that of Katbamna *et al.*'s (2004) research on the stereotypes of South Asian carers. They concluded that the carers in their study experienced everything from cultural and religious misunderstanding to racism.

In response to the above, I developed a strong interest in Muslim family carers with a concern that they were vulnerable victims of racist stereotypes and Islamophobia. These views were substantially compounded by a meeting with an eminent Theologian who predicted that most of my respondents would be highly uneducated, and that this factor would have a significant influence on my findings. I found these assertions to be worryingly homogenising on his part, but also intriguing and fascinating.

Later that year, as part of my Master's degree, I was required to carry out a small research project relating to my proposed PhD research. My experiences undertaking this study also shaped my perceptions. This is described in more detail below.

### **1.3 ENTERING THE FIELD FOR THE FIRST TIME: LESSONS FROM A SMALL RESEARCH PROJECT**

For my Master's degree in Research Methods (Sociology), I was required to carry out a small piece of empirical work, which would support my proposed PhD project. This was undertaken during the summer of 2005. I planned to access three Muslim community leaders and invite them to be interviewed about their experiences and perceptions of illness and disability. I hoped that they would subsequently act as 'gatekeepers' for future access to Muslim family carers. I began 'cold calling' Mosques, community centres and local groups at the beginning of July. I had reasonable success and managed to get agreement from various Imams and respected Muslim community group leaders who said they were willing to be interviewed. However, all contact with these potential respondents was lost after the 7/7 bombings in London. Following this event, only one of the potential interviewees agreed to speak to me. He explained his concerns that I may actually be a journalist or policewoman working covertly to publicly expose and falsely implicate him and his community. On the 12 July 2005 I wrote in my research diary, 'out of fear for their civil liberties, the Muslim community has closed its doors to outsiders'.

With some difficulty I eventually succeeded in managing to interview an Imam, a Muslim community group leader and a Muslim religious leader. All three respondents were concerned about our meeting being recorded, and two out of the three interviewees refused to answer a number of my questions. The content of the interviews also seemed to be heavily influenced by recent events. Below is an extract from Asad's (a Muslim community group leader) interview, which demonstrates this difficulty:

Interviewer: What are the Islamic teachings of illness and disability?

Asad: *Qur'an* is very peaceful. I would like to use this opportunity to make this very clear. We condemn violence. That is not Muslim.

These experiences were extremely relevant in shaping my subsequent conceptions about the research. In particular, they shaped my assumptions about how access to health and social services would be experienced by Muslim family carers, which I became increasingly interested in exploring.

What is most striking about what then came to be the central thrust of my argument in this thesis is the diversity of experience of the carers in this study. Although some respondents were indeed vulnerable and found accessing services difficult due to language, religious and cultural barriers, my findings also strongly suggest that Muslim family carers are not a homogenous group, and their experiences as carers are ultimately

dependent upon the situational circumstances that intersect within their lives. As such, many of my respondents were empowered and vocal Muslim women, often active in raising awareness about disability within Muslim communities, or campaigning for services to be religiously and culturally sensitive. Consequently, these findings aim to provide a deeper contextual understanding to existing literature pertaining to the experiences of care within diverse religious groups.

## **1.4 THESIS OUTLINE**

Chapter two explores the key underlying existing theoretical and empirical literature relevant to this research. It specifically focuses on three themes that weave throughout the three data chapters (Chapter 4-6). These themes are defined as *Perceiving Religion*, *Doing Care*, and *Negotiating Families, Ties and Kinship Groups*.

Chapter three addresses the methodological underpinnings of the research. It explores my social constructionist positioning, and how this epistemological standpoint informed a decision (among other practical factors imposed on the study) to employ semi-structured interviews as the best method for exploring my three research questions introduced above. The chapter explains how twenty-eight Muslim family carers were accessed for interview, along with a further fifteen 'professionals', whose occupations specifically related to supporting Muslim family carers. In most cases, these interviews were conducted with staff, or

associated professionals at four specialist Muslim carer support groups, who acted as gatekeepers to the majority of interviews conducted with carers. These interviews widened my understanding of how the Muslim family carers accessed support for their caring role, and furthermore, how the specifically *Muslim* carers' organisations constructed a religiously and culturally appropriate space through which access to health and social services for the cared for relative could be mediated.

Chapters four to six comprise the three data chapters, which explore and analyse the accounts given by the Muslim family carers in the study. The main themes of each chapter are introduced below.

Chapter four explores the extent to which, and in what ways, Muslim family carers interviewed for this research thought of their caring roles as being informed by their religious beliefs. These views are framed by Weber's (1922) theory of theodicy. This analysis reveals the complexities within the respondents' constructions of religious beliefs pertaining to their often difficult and demanding circumstances. It is argued that this is due in part to the situational factors affecting the carers' circumstances, which result in the adoption of belief systems that work to comfort the respondent. Furthermore, these religious beliefs regularly intersected with the 'lived' experiences of caregiving. In this way, respondents regularly spoke about how their caring role was bestowed with spiritual significance, which compensated for missed Muslim religious practices such as praying five times a day (*Namaaz*)

and going on pilgrimage to Mecca (*Hajj*). These responses are framed by a relatively new body of literature pertaining to the 'lived' experiences of everyday religion (Ammerman, 2007; McGuire, 2007; 2008).

Chapter five analyses how British state services were perceived, experienced and negotiated by the Muslim family carers in the study. Mary Douglas's (1966) work on 'purity and danger' is particularly relevant to some parts of the chapter, whereby the imposition of symbolic boundaries demarcating 'pure' or 'dangerous' spaces seemed to assist respondents in retaining a sense of religious difference from the imposition of mainstream secular British society. Judith Okely's (1986) anthropological work on *The Traveller-Gypsies* provides an interesting conceptual framework with which to analyse how the participants carefully managed and controlled their cared for relatives' access to health and social services. This analysis reveals a fundamentally gendered approach among carers in the study about how they perceived access to state services. Here, Muslim females with learning disabilities were regularly perceived as being particularly vulnerable to the dangers of secular society, especially in terms of their honour (*Izzat*), which was often presented in conjunction with the reputation of the family. These perceptions were exacerbated by accounts of negative experiences whilst attending a mixed sex service, which often involved a friendship developing between a female with learning disabilities and a male service user. Consequently, carers often

reported completely restricting their female cared for relatives from accessing any form of social or care activities outside of the home.

Chapter Five then compares these accounts with how carers of male relatives negotiate access to health and social services. Consistent with existing literature, carers of males tended to 'manage' rather than 'prevent' attendance at social activities (Hussain, 2005). Here, respondents presented negative accounts of services failing to cater to religious and cultural requirements. Dominant themes included the lack of provision of *Halal* food, an absence of rituals for washing after going to the toilet (*Istinja*), and consuming alcohol, as well as taking a cared for relative to a place that sells alcohol. Consequently, carers described how they managed these incursions by providing food themselves, washing their cared for relative upon their return from a service, and preventing the service from taking family members to places that serve alcohol.

Chapter six explores the carers' social networks. Analysis of the data reveals that carers predominantly report two forms of support, the family and the Muslim carers' organisation (from which the majority of carers were sampled). As the carers spoke in most depth about their complex relationships with the family, more space is devoted to understanding how this form of support was perceived, allocated and negotiated. The increasingly popular concept of social capital is introduced here as a theoretical framework for understanding how membership to social



networks can be both enabling and restricting for accessing resources of support.

Anthias's (2007) arguments regarding the uneven distribution of social capital within ethnic ties and networks also provides an important conceptual framework from which this chapter explores the hierarchical nature of both being a primary carer, and of supporting carers within their everyday routines. In support of existing literature, the allocation of domestic care responsibilities were primarily gendered, with accounts indicating that the majority of care labour was undertaken by women (Dalley, 1996; Finch and Mason, 1993; Lewis and Meredith, 1988; Oakley, 1974; Sullivan, 2000), however, a further division of labour between women is also explored. Here, women married into the family were often cited as undertaking more significant amounts of care than other family members.

The positive role of the family for providing support to carers is also explored. The findings here support a growing body of literature arguing that the family can continue to play an important and significant role in contemporary society, even when family members migrate to other countries, which was a salient factor for many respondents (see Goulbourne *et al.*, 2010; Zontini, 2006; 2010). The chapter then examines the negative effects of family ties and networks. Obligations and expectations about how care should be undertaken without the additional support of outside organisations seemed to place constraints

on some of the respondents, which ultimately leads to an analysis of how the social location of the carers in the study within the networks to which they belong shapes how access to support resources are experienced both within the family, and when accessing formal organisations. Finally, the chapter focuses on the role of four specialist carer support groups, whose specific function it is to support Muslim family carers. The voices of the professionals in the study are heard within this section as their contributions support the thesis that services provided by these organisations offer an interesting and innovative form of bridging social capital to health and social services. Here, professionals often argued that they perceived their occupational role as mediating or 'bridging' the gap between Muslim family carers and their access to health and social services.

Chapter seven presents the thesis conclusion. The main conceptual themes that emerged from the data will be revisited, and a discussion is presented about the original contributions that these themes offer to sociological knowledge. Suggestions are also made for further research in this area.

## **CHAPTER TWO**

# **RELIGIOUS BELIEF, CAREGIVING, AND NEGOTIATING NETWORKS OF SUPPORT: A CRITICAL REVIEW OF LITERATURE**

### **2.1 INTRODUCTION**

The 2001 National Census revealed a number of interesting findings pertaining to the experiences of Muslim family carers in Britain. In particular, it showed that Pakistanis and Bangladeshis, who make up the majority of the Muslim population within Britain (nearly sixty percent), were more likely to undertake informal care than any other ethnic group (Young, *et al.*, 2005). Furthermore, within this Census, Muslims reported experiencing the worst health, being more likely than any other religious group in Britain to suffer from a long-term illness (ONS, 2001). These findings expose a potentially interesting gap in knowledge about caring within British Muslim families.

Sociological studies of care and religion have overwhelmingly focused on Christian denominations (Dollahite, 2003; Poston and Turnbull, 2003; Skinner *et al.*, 2001; Trelour, 2002). Furthermore, research on care and ethnicity has tended to concentrate on South Asian communities, wherein Muslim carers have often been subsumed within the findings (Adamson and Donavon, 2005; Ahmed and Rees Jones,

2008; Atkin *et al.*, 2002; Hepworth, 2003; 2005). As articulated in Chapter One, this body of literature provides an invaluable addition to knowledge about the diverse experiences of care within British South Asian communities, however, it cannot be assumed that Muslim family carers are sufficiently represented by conclusions drawn from these studies. In this way, it may be argued that research specifically focusing on Muslim family carers would provide an important addition to knowledge. As such, my research intends to contribute to existing knowledge by specifically exploring how being Muslim informs and shapes the perceptions, performances and negotiations of caregiving within the family.

Accordingly, this chapter will critically discuss the key underlying issues involved in undertaking a study focusing on the perceptions, performance, and negotiations involved in the experience of being a Muslim family carer. In its organisation, literature has been grouped together to form three themes loosely based on the research questions identified in the previous chapter.

The first theme titled *Perceiving Religion* pertains to the first research question. It concerns how religious belief is perceived and experienced by ‘non-expert’<sup>3</sup> individuals in everyday context. In view of this, literature pertaining to the private, everyday and ‘lived’ experiences of religion is explored. In this way, it is argued that valuing these religious beliefs

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<sup>3</sup> The term ‘non-expert’ is borrowed from Ammerman (2007), who uses it to create a distinction between the institutional voices of religious organisations (professionals), and lay individuals, everyday religious adherents, without any institutional authority.

allows us to understand in more depth how religion continues to inform and shape people's everyday lives. Weber's concept of theodicy is also examined as a useful framework for understanding how religious adherents make sense of suffering and tragedy within their lives. This is deemed to be a particularly salient theory for exploring this initial research question. Finally, a brief overview of the existing literature on interpreting the *Qur'anic* teachings of illness and disability is addressed.

The second theme titled *Doing Care* pertains to the second research question. Here, literature exploring the undertaking or performance of care is examined. The section examines the distinct nature of undertaking informal care (Lynch, 2007), particularly in relation to the diverse intersections of the caring experience, namely, gender, ethnicity and religion. It also explores how health and social services are either accessed or not accessed based on a range of factors identified within the literature. These include institutional barriers, cultural and religious sensitivities, and attempts to uphold a sense of ethnic or religious identity against the perceived threats of assimilation.

The final theme titled *Negotiating Families, Ties and Kinship Groups* pertains to the third research question. Here the concept of social capital is introduced and analysed as an important tool for understanding how care is negotiated, allocated and supported within families, ties and communities. It also explores how resources of

support may be experienced in distinct ways along gendered and ethnic lines.

## **2.2 PERCEIVING RELIGION: ‘LIVED’ RELIGION, WEBER’S THEODICY AND THE *QUR’ANIC* RESPONSES TO ILLNESS AND DISABILITY**

This section explores existing literature relating to the religious dimensions of this research. It begins with a discussion of some contemporary perspectives on the sociology of religion that focuses on the private, everyday, or ‘lived’ experiences of religion. This theoretical framework is of particular relevance here in that it values the beliefs and practices of the ‘non-professional’ religious adherent (Ammerman, 2007). As this study wishes to hold at its centre the views and experiences of Muslim family carers, most of whom do not purport to be religious professionals, these perspectives are of particular significance. This is followed by an analysis of Weber’s theory of ‘the problem of theodicy’. Theodicy is loosely defined as the religious responses to suffering (Musick, 2000). Weber’s concept of theodicy provides a useful theory for understanding how the carers in the study employ religious beliefs to shape, inform, cope and make meaning from their caring role. Finally, this section explores the relatively small body of literature analysing popular interpretations of the *Qur’an*’s teachings of illness and disability. The section finishes with a summary of the main points.

### **2.2.1 VALUING THE PRIVATE, EVERYDAY AND ‘LIVED’ RELIGIOUS EXPERIENCE**

‘When we focus on religion-as-lived, we discover that religion – rather than being a single entity – is made up of diverse, complex, and ever-changing mixtures of beliefs and practices, as well as relationships, experiences, and commitments’ (McGuire, 2008: 185). Religion in modern society is arguably complex. Most, however, agree that religion continues to play an important role for millions of individuals (Selway and Ashman, 1998), but that the nature of religious participation in institutional settings has fundamentally shifted and in some cases declined (Ammerman, 2007; Davie, 2004; Luckmann; 1989; Pace; 2007). In response to these changes, theorists are increasingly acknowledging the ascendancy of the self in the fashioning of individual and social lives by exploring the ‘private’, ‘lived’ or ‘everyday’ experiences of religion. Ammerman (2007: 5) explains that ‘[t]o start from the everyday is to privilege the experience of nonexperts. [...] Everyday religion may happen in both private and public life, among the privileged and nonprivileged people. It may have to do with mundane routines, but it may also have to do with the crises and special events that punctuate those routines’.

This sub-section examines how a relatively new body of literature pertaining to the ‘lived’ and ‘everyday’ experiences of religious life for individual people has emerged from more classical preoccupations with the societal and institutional role of religion. It then goes on to examine

how social theorists and researchers have adopted these perspectives to explore how religion continues to play an important role for many people in contemporary society within both their public and private lives (Davie, 2004). These perspectives push the boundary of what has previously been considered to be 'legitimate' religious participation, and allows the sociology of religion to value not just the institutionalised voices of religious professionals, but the 'lived' religious experiences of everyday people (Ammerman, 2007).

Many theorists have argued that the sociology of religion has classically ignored private aspects of religious life, favouring explorations of religion in the public spheres of a predominantly male society (Aldridge, 2007; Ammerman, 2007; Davie, 1994; Luckmann, 1989; Woodhead, 2008). Berger (2007: v) argues that '[m]uch of the sociology of religion has dealt either with [...] the internal condition and the societal role of churches – or with survey data covering the beliefs and behavior of large populations. Obviously, both procedures have yielded important insights. But what both have in common is remoteness from much of what constitutes the reality of religion in the lives of many people'.

From this perspective, a relatively new body of literature has emerged that examines the 'lived', 'everyday', or micro-sociological dimensions of religion, which is the focus of this section. Collins (2010) argues that micro-sociology provides a technique for examining not just what people say, but what they actually do and experience. Similarly to



Berger (2007), Collins acknowledges the importance of meso and macro sociologies of religion<sup>4</sup>, which he recognises as showing 'different things' (p.2) at their level of analysis. Berger (2007: vi) goes on to explain how survey data on religion, synonymous with macro-sociology, whilst providing useful data, is often susceptible to the respondent both misinterpreting the responses and 'fiddling with the facts' to make them appear either more religious or more secular than they actually are. Consequently, Berger advocates the rich data provided by qualitative studies of how religion is experienced by people in their everyday lives and argues that such a valuable contribution develops an understanding of other central themes in the sociology of contemporary society.

Aldridge (2007) points out that the majority of the founders of sociology were atheists and therefore preoccupied with the replacement of religion with secular social institutions. He argues that applying classical sociological thought to modern theorisations about religion is therefore problematic in that it subjectively encouraged a celebration of rational, Western scientific progress as the only path to knowledge. Like Berger (2007), Aldridge (2007) encourages explorations of the private aspects of religious participation by arguing that religion often transcends conventional public/private boundaries by placing on the public agenda

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<sup>4</sup> Collins (2010: 2) defines the meso level of religion as including church organisations, religious movements, religious demography and the entwining of religions with politics. He defines the macro-sociology of religion as showing patterns of historical change, innovation, conflict, rise and fall, religious market processes and the place of religion in the social history of culture, states and economies.

issues about identity and culture that some would rather remain in the private domain. He credits Davie (1994) as demarcating an important shift in how the sociology of religion approaches the study of religious participation and belief.

By examining the religious situation in the North-West of England, Davie (1994) coined the term 'Believing Without Belonging', which refers to the decline in religious participation but the continuation of privatised religious belief. Moreover, she argued that contemporary Britain 'is not as secular' (p. xii) as one might have imagined. She challenged popular assumptions about the secularisation<sup>5</sup>, or decline of religion in modern society, arguing that personal religious beliefs, not necessarily sanctioned by official church teachings are increasing. What was of particular interest to Davie (1994) was the methodological mismatch between statistics relating to religious practice, and those which indicate religious belief. In this way, variables concerning feelings and experiences pertaining to religious belief indicated considerable persistence in Britain. Variables measuring religious orthodoxy, ritual participation and institutional attachment, however, displayed a very 'secularised' view of British society.

During her long career, Davie has continued to advocate the study of the 'individualised, detached, undisciplined and heterogeneous' (2000:

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<sup>5</sup> Berger (1967: 107), a major proponent of the secularisation thesis (although he interestingly changed his perspectives in 1999) defines the concept as 'the process by which sectors of society and culture are removed from the domination of religious institutions and symbols'.

120) aspects of religious belief that she considers to be far more significant than the declining patterns of church attendance. Although aspects of Davie's work have received criticism<sup>6</sup>, her contributions pave an important path for subsequent researchers in the sociology of religion, which values the complexities of private religious belief, in addition to public religious practice and participation.

In response to these complexities, Beckford (2003) attempts to avoid defining religion, arguing that it is more rewarding to investigate what people count as religious, and how this translates into beliefs 'in particular situations'. He cites previous research on young British and French Muslims, pointing out that Muslim identities are constructed in ways that are appropriate to the situation. In this way, one 'Muslim identity' will be specific, or more or less appropriate to other 'Muslim identities' in a different situation. Beckford's arguments acknowledge the fluidity of identity, and recognise how beliefs can be adapted, intensified and diluted as a response to situational factors.

Consistent with Beckford's (2003) ideas, Ammerman (2007) employs the term 'everyday religion' to describe the 'everyday ways modern persons relate to the things they experience as religious or spiritual' (p.5). She describes her edited book as 'a series of dispatches from the

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<sup>6</sup> Davie received particular criticism of her term 'believing without belonging', which some have argued may be misleading due to the terms 'believing' and 'belonging' being open to multiple interpretations (Aldridge, 2007). Davie (2000) has responded to these criticisms, arguing that the term intends to 'catch a mood' (p.116) and suggest an area of enquiry rather than form the basis for empirical enquiry. Consequently, Davie argues that the term should be used with caution and not operationalised 'too severely' (p.116).

field' (p.4), whereby, questions are raised about how religion is understood and interpreted in modern society. Like Beckford (2003), Ammerman is sceptical about the usefulness of defining religion, asserting that the contributors to her volume value what their respondents experience as religious or spiritual rather than placing sole importance on 'official' or 'professional' perspectives. Ammerman's reflection on the book's content highlights how in each chapter, some form of religiosity is woven into the fabric that makes up the respondents lives. Furthermore, the collective findings suggest that modern religious beliefs do not tend to conform to 'what religious officials would like to see in a faithful follower' (p. 221). Ammerman argues that current theoretical perspectives on the sociology of religion (such as the secularisation thesis) do not adequately explain the findings in her volume:

Neither "exposure to modernity" nor the range of available choices nor the "strictness" of the religious community seems to explain very much of what we have seen [...] The people we have met in the field are more and less attentive to spiritual matters, but what they see and hear and do when they do pay attention is often subtly shaped by the institutions that have carried the dominant religious traditions in those places (p.219).

Ammerman's work pushes the boundaries of what has previously been considered 'legitimate' religious beliefs, and exposes a potential gap in knowledge about how faith is experienced or 'lived' in everyday modern

society. Her perspectives also question the need for new theoretical frameworks for analysing religion.

In the same vein, McGuire (2008) has significantly contributed to this gap in knowledge by exploring what she terms as 'lived religion', which refers to faith and practice in everyday life. Like Davie (1994; 2000; 2004) and Ammerman (2007), McGuire acknowledges that religion has changed within modern society (rather than declined), which leads her to criticise current concepts for analysing religion.

[N]ot only do religions change over time but also what people understand to be "religion" changes [...] Too often, our concepts for describing and analyzing individuals' religions simply fail to capture how multifaceted, diverse, and malleable are the beliefs, values, and practices that make up many (perhaps most) persons' own religions (p.5).

Consequently, McGuire adopts a broad conception of religion to encompass individuals' religions 'as lived' in a particular time and cultural setting (p.12). She argues that the concept of 'lived religion' distinguishes the 'actual' experiences of religion from prescribed institutionally defined beliefs and practices, whilst continuing to value professional religious voices.

For McGuire, it is important to explore the 'complexities, apparent inconsistencies, heterogeneity and untidiness of the range of religious

practices that people in any given culture and period find meaningful and useful' (p.16). McGuire explains that focusing on lived religion enables an analysis of how religion is employed as a cultural resource for aspects of identity and commitment (p.187). McGuire's perspectives offer a constructive theoretical framework for analysing studies of religion in modern society. Researchers have increasingly adopted lived religion as a conceptual framework for empirical research, which is explored in more detail below (see also Cadge and Howard Ecklund, 2007; Helland, 2005).

Ramji's (2007) study of the gender dynamics of young British Muslims provides a useful example of how valuing the lived experience of religion may be employed within empirical research. Her research highlights how religion is used as a resource for legitimising and challenging cultural practices. She explored how young British Muslim men and women articulated their gendered identities. Using data collected from 20 in-depth interviews, she observed that the young British Muslim women in her study rejected the patriarchal interpretations espoused by the men in her study by arguing that their religion had been misinterpreted:

The problem was not with their religion rather how it had been (mis)interpreted. For these women it was their generation's responsibility to get this message out to the wider community. [...] The respondents were able to distinguish between patriarchal cultural practices and Islamic teaching. They were not about to abandon Islam, rather to

reclaim it for Muslim women (p.1182).

Ramji (2007:1186) analyses how the British Muslim men in her study used their religion as a resource to mobilise Islam in an attempt to legitimate their dominance within the Muslim community. Conversely, the women in the study used similar themes to challenge traditional understandings of their position within the community and mobilise greater status for themselves. Ramji's approach to the study of religion enables her to explore the complexities and contradictions of religion in everyday modern life. She argues that the 'mobilization of religion is often ambivalent, contradictory and intersected with other social differences, particularly class' (p.1172). Ramji's findings provide support for how the lived experiences of religion can intersect with other social divisions such as gender. These assertions may also suggest that the impact of religion may also be experienced in other social situations such as caring for a family member.

Although there has been very little research carried out on the lived experiences of religion for Muslim family carers, Dollahite (2003) provides an illuminating account of the influence of Mormonism on fathers caring for a child with 'special needs'. His methodological approach to the study allowed his respondents to 'speak at length and in depth about their beliefs and experiences' (p.241), and encouraged the sharing of personal stories and meanings. Consequently, Dollahite was able to explore how Mormon religious beliefs shaped how the

fathers in the study interpreted their caring role. He reported that most respondents adopted a sense of 'sacred responsibility' to care for their child, which was freely chosen and provided meaning and identity to the fathers in the study. He concludes by arguing that 'there is a special power in religion's appeal to the supernatural that strengthens commitments and enhances the fathering of children with special needs' (p.249). He also asserts that further research in this area, focusing on other faith communities would provide a greater insight into the role of religion for fathers caring for a child with 'special needs'. Dollahite's study highlights an important gap in knowledge pertaining to how religion supports and influences family carers who identify as being religious.

The above discussion explores how theorists and researchers of the sociology of religion have responded to perceived changes in how religion is experienced in modern society. The theoretical contributions of Davie (1994; 2000; 2004), Beckford (2003), Ammerman (2007) and McGuire (2008) provide a framework for exploring the 'private', 'everyday' or 'lived' experiences of religion. Their work highlights the importance of valuing what individuals count as religious, alongside focusing on the 'professional' voices of religious experts. These perspectives are supported by the findings in Ramji (2007) and Dollahite's (2003) research. Their studies provide an insight into how valuing the 'lived' or 'everyday' experiences of religion reveals that faith continues to be used as a resource (for the respondents in their study)



to contextualise, understand and justify life's complexities, contradictions and crises. Moreover, that official religious beliefs are contested and reconstructed when lived out in the everyday context. The relative newness of valuing these aspects of religious belief leads Ammerman (2007: 234) to conclude that '[s]ociologists of religion still have a great deal left to study' (p.234).

### **2.2.2 THE APPLICATION OF THEODICY TO MUSLIM BELIEFS ABOUT SUFFERING, DISABILITY AND CARE**

The previous sub-section addressed how modern conceptualisations of religion allow for understandings about how faith affects individuals in their everyday lives. Valuing these beliefs within empirical research reveals how religious belief can be used as a resource to contextualise, understand and justify life's complexities, contradictions and crises. Max Weber (1922) also analysed the religious response to crises and suffering in his *Sociology of Religion*. Although the focus of this contribution provides support for what he believed to be the secularisation or 'disenchantment' of society, Weber's work on 'the problem of theodicy' enhances an understanding of how suffering and 'misfortune' is spiritually explained. This section examines Weber's theory of theodicy, and its application to modern sociological research on suffering, misfortune and crises.

An analysis of how the religions of the world address crises, suffering and misfortune, such as being afflicted with illness or disability was of

particular importance to Max Weber (1922), who popularised the term 'the problem of theodicy'. Theodicy, simply defined as religious beliefs relating to the meaning of suffering (Musick, 2000) is 'problematic' for Weber in terms of the question: if God is omniscient, then why does evil and suffering exist? He argues:

The more the development tends toward the conception of a transcendental unitary god who is universal, the more arises the problem of how the extraordinary power of such a god may be reconciled with the imperfection of the world that he has created and rules over (Weber, 1922: 138-139).

Weber argues that the problem of theodicy has been solved in various ways. In his *Sociology of Religion* he discusses in detail three solutions, or 'pure types'. The first solution Weber discusses is the assurance of just equalisation through 'messianic eschatologies' (1922: 139). Weber describes that the solution asserts that a great hero or god would 'place his followers in the position they truly deserved in the world'. Prophets spoke of the coming of such a kingdom, however, when such promises are 'unduly delayed' (p.140), the inevitable solution was to assume that consolidation be sought in 'genuine otherworldly hopes' (p.140) or a just future in the afterlife. Weber relates this solution to a point about class. If those who have suffered in life will be rewarded in the afterlife, then a concern arises for those whose earthly needs have been met. Thus, these concerns are limited to the wealthy classes. This conception inevitably leads to what Weber describes as 'the ultimate theoretical

conclusion' (p.142), whereby 'the omnipotent creator god must be envisaged as being beyond all the ethical claims of his creatures, his councils impervious to human comprehension' (p.142-143). As such, human justice is inapplicable to his behaviour and action.

The second 'pure type' solution to the problem of theodicy that Weber presents is 'dualism', which denotes the eternal struggle between good and evil. He devotes relatively little space to an analysis of this solution, and describes it simply as the inevitable suffering experienced as a result of the continuous purification of the light from the contamination of the darkness. Weber asserts that this solution inevitably produces a powerful eschatological emotional dynamic.

The final solution to the problem of theodicy Weber argues is the most complete. This is described as being the special achievement of the Indian doctrine of *karma*. Here, the world is viewed as a 'self contained cosmos of ethical retribution' (p.145). Good and bad behaviour in one's life will be rewarded and punished in the future reincarnations of an individual's soul. The ultimate *karmic* goal is for the merits within this world to rebirth the soul into life in heaven, however, time within heaven only lasts until 'one's credit balance of merits has been completely used up' (p.145). The advantage of this solution to the problem of theodicy is that each individual forges his own destiny. In this way, Weber argues that:

Strictly speaking, there is no sin, but only offences against one's own clear interest in escaping from this endless wheel, or at least in not exposing oneself to a rebirth under even more painful circumstances. The meaning of ethical behaviour may then lie, when modestly conceived, either in imposing one's chances in his next incarnation or – if the senseless struggle for mere existence is ever to be ended – in the elimination of rebirth as such (1922: 146).

Weber concludes his discussion by arguing that only a few religions have produced a pure solution to the problem of theodicy. Furthermore, most religions of salvation have attempted to combine the various pure types as a result of mutual interaction that exist between those religions and its followers, and to satisfy the 'diverse ethical intellectual needs of its adherents' (p.147). Consequently, Weber calls for the differences between the religious theories of God's relation to the world and man to be measured by their approximation to the three pure type solutions to the problem of theodicy.

In terms of its application to sociological research on religion, Turner (1981) argues that:

Any sociology which comes up against pain and death, accident and misfortune, inequality and injustice in social life must necessarily find itself confronted with the problem of theodicy (p.170).

Moschella *et al.* (1997) also share Turner's enthusiasm for the concept of theodicy. In their study of the religious responses to cancer, they attempt to measure the 'theodological' beliefs of cancer patients. Using questionnaires, Moschella *et al.* analysed what they regarded as the 'major categories of theodicy or modes of reconciling suffering with a morally good God' (p.17). They conclude by arguing that the majority of respondents endorsed a theodicy that claimed that there was spiritual purpose to their suffering, and such purpose could not be explained or understood. It is interesting to note that Moschella *et al.*'s findings adhere, as predicted, to the first 'pure' solution to the problem of theodicy that Weber discusses (that the human mind is unable to comprehend the will of God). Moschella *et al.* (1997) argue that whilst mainstream debates recognise the importance of religious belief in the adjusting to medical illness, literature relating to people's theodicies about suffering are 'notably absent' (p.17). Furthermore, literature pertaining to Muslim theodicies about suffering are somewhat lacking. Bowker's (1970) influential work on the *Problems of Suffering in the Religions of the World* includes a detailed exploration of Islam and the *Qur'an*.

For Bowker, the theological problem that Islam encounters with the experience of suffering is that it conflicts with the belief that God is omnipotent. Consequently, he observes that the *Qur'an* repeatedly states that suffering can only be understood as being encompassed within God's omnipotence. He argues:

In effect, the Quran says, 'Take the concept of omnipotence seriously: if your imagination is not too small, then suffering cannot be a problem, because the facts of suffering must necessarily be contained within the omnipotence of God' (p.103).

In this way, suffering is understood as being controlled by God and is therefore purposeful. If suffering is purposeful and an omnipotent God controls the universe, then suffering must be the direct purpose of God. Bowker continues his analysis by observing that these beliefs manifest in two explanations (or theodicies) about suffering. Firstly, suffering is experienced as a punishment or cleansing of one's sins. Secondly, suffering is endured as a test from God. Ahmed (2000) concurs with Bowker's analysis in his exploration of Muslim understandings of health and disease. He describes how many Muslim scholars argue that based on the teachings of Muhammad, 'sickness and tribulation bring an opportunity to earn rewards through patience and steadfastness and are a cause for the cleansing of one's sins' (p. 31).

Although Bowker (1970) and Ahmed's (2000) analyses of the Islamic teachings of suffering, illness and disability provide an important contribution to knowledge, very little empirical research has specifically explored how these teachings are translated into the lived experiences of Muslims affected by illness and disability and their families.

Furthermore, many studies examining family carers allude to their respondents expressing seemingly 'theodological' explanations for their situation (e.g. Cox and Monk, 1993; Hayward and Madill, 2003; Levin,

2001; Poston and Turnbull, 2004; Skinner *et al.*, 2001) without employing Weber's theories as a conceptual framework to analyse these accounts. In this way, a potentially interesting gap in knowledge remains unaddressed within sociological literature, especially for Muslim family carers, whose religious beliefs remain unexplored in relation to how faith may impact on and shape how their caring role is perceived, experienced and understood. The subsection below examines in more detail the relatively small body of knowledge in this area.

### **2.2.3 EXAMINING INTERPRETATIONS OF ILLNESS AND DISABILITY IN THE QUR'AN**

As the previous chapter stated, one of the aims of this research is to fill a specific gap in knowledge by exploring the religious beliefs of specifically Muslim family carers. It is therefore pertinent to examine the small body of literature that discusses discourses of care, disability and illness within the *Qur'an*. This is a particularly small body of literature because although caring is often regarded as an Islamic duty (Dhami and Sheikh, 2000), passages of the *Qur'an* specifically focusing on disability or illness are difficult to locate. Moreover, some argue that the concept of disability, in the conventional sense, is not found in the *Qur'an* (Bazna and Hatab, 2005). Nevertheless, as the short discussion below demonstrates, an understanding of the *Qur'an*, like the religious texts of the majority of world religions is based upon an interpretation of its meaning. In this way, some scholars interpret passages of the

*Qur'an* to specifically address issues of disability. Below, a very brief introduction to the main Islamic beliefs contextualises the ensuing discussion examining the literature on disability and the *Qur'an*.

The faith of Islam grew in the mid seventh century during a time of accentuated political and social unease (Rippin 2001). Over a period of twenty-two years Muhammad *ibn 'Abd Allāh* wrote scriptures revealed to him from visions of the final message from God, or *Allah*. These scriptures form the basis of the Muslim faith known as the Holy *Qur'an* (Koran). Biographies of Muhammad's life (*Sira* or *Hadith*) are scrutinised, and his life held up as a personification of perfection (Bowker, 1970; 1991; Rippin, 2001; Ruthven, 1997). The basic duties of each Muslim are known as the Five Pillars of Islam (See Appendix 02).

The *Qur'an*, like many other religious texts, has a wealth of debate surrounding its meaning. Literal meaning versus interpretation of the *Qur'an* causes division amongst religious believers and scholars (Aldridge, 2000). A common example here is Islamic fundamentalism. Islam literally means 'submission to the will of *Allah*' (Ruthven, 2000) and Islamic fundamentalists believe that 'The whole of life is to be ordered solely on Islamic principles' (Aldridge, 2000: 131). As such, concepts of democracy and modernisation are considered to be evil and threaten a purely Muslim way of life. Contrary to some media stereotypes of Islamic fundamentalism however, most Muslims do not subscribe to these interpretations of the *Qur'an* (Aldridge, 2000). Miles



(2002) argues that taking a literal meaning of the *Qur'an* is worthless, as it requires elements of interpretation for it to make sense to the reader. He quotes a passage from Abdullah Yusuf Ali's translation (1989: 419) of *Surah* 8 verse 22: "For the worst beasts/In the sight of Allah/Are the deaf and dumb/Those who understand not." This passage could offend disability activists, however, Miles (2002) argues that reading all of the *Surah* reveals its metaphorical connotations and should not be interpreted negatively.

Contrary to Miles, Turmusani (2001) presents a damning narrative of the *Qur'an*'s representation of disability. She argues that '[i]cons of Islamic enemies, for example, are repeatedly portrayed as having physical disfigurements' (p.77). Consequently, families (in particular Mothers) of those with disabilities are shamed and blamed. These accusations are not exclusive to Islam. Barnes (1992) notes that in the Bible there are over forty references to 'the cripple' being associated with sin or evil. The story of Jesus healing a boy with epilepsy by driving a demon away saliently demonstrates this point (Matthew 17 verses 14-20, cited in the United Bible Societies, 1994)<sup>7</sup>.

The polysemic quality of Miles's (2002) arguments concerning the interpretation of the *Qur'an* (above) is characteristic of the sacred writings of most world faiths (Holm and Bowker, 1994). As such, religious beliefs about illness and disability will be dependent, at least in

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<sup>7</sup> This is not to suggest that negative representations of disability are exclusive to Islam and Christianity. Barnes (1992) is included here as an example of criticisms levelled at other world religions in response to how disability is constructed.

part, on the situational factors that intersect with those affected, their families, and their religious communities. It is acknowledged that more research needs to be carried out on people's experience of faith when affected with illness or disability (Dollahite, 2003; Selway and Ashman, 1998). Existing research on this topic has predominantly focused on the study of Christian denominations, and relatively little is known about the lived Muslim responses to illness and disability. In response to this gap in knowledge, this research aims to explore the specifically Muslim responses to care, illness and disability within the family.

#### **2.2.4 SUMMARY**

The above discussions have highlighted a potentially interesting gap in knowledge pertaining to the religious beliefs of Muslim family carers. This manifested itself in three distinctive sub-sections. The first sub-section revealed how many aspects of the classical sociological assumptions about religion have required updating to represent a more accurate picture of religion in contemporary British society (Beckford, 1990). This picture requires the sociologist of religion to value the religious beliefs practised within the private spheres of society (Davie, 1994), often outside of the pre-prescribed settings of religious institutions such as Churches, Mosques and Synagogues (Ammerman, 2007). As a relatively new concept, this exposes many areas of religious experience left unknown to the sociology of religion. Within this, some researchers have suggested that additional research needs

to be carried out on carers who identify as religious, as previous research has found that religious belief can be an important factor for assisting the carer with coping, understanding and coming to terms with their caring role (Dollahite, 2003).

The second sub-section discussed Weber's concept of 'the problem of theodicy' (1922). The concept of theodicy, or religious explanations for suffering are particularly relevant for this research in that it provides a useful theoretical framework for understanding how the carers in the study employ religious beliefs to shape, inform and cope with their caring role.

The final sub-section explored the small body of literature pertaining to interpretations of illness and disability within the *Qur'an*. Like the majority of religious texts, there is a wealth of debate surrounding its meaning. The mixed findings explored within the subsection suggest that due to the diverse explanations for *Qur'anic* teachings about illness and disability, there may be little consistency in the Islamic explanations given by the Muslim family carers in the study.

As this thesis specifically links being Muslim with informal care, the following section critically examines the literature on informal caregiving, and how this can be shaped by perceptions and beliefs about health, illness and disability.

## **2.3 DOING CARE: PERCEPTIONS, PERFORMANCE AND ACCESSING SERVICES**

This section critically examines existing literature on how Britain's minority ethnic and religious carers undertake their caring role. In particular, how the intersections of gender, ethnicity and religion impact on how care is negotiated and allocated within the family. This precedes two subsections that explore how British carers, and in particular, South Asian and Muslim carers manage, control and are prevented from accessing health and social services.

This section also acknowledges that previous research has contributed important knowledge of how South Asian and Muslim communities are often prevented from accessing health and social services due to language barriers and insufficient attention to religious and cultural requirements. However, recognising the agency of certain groups to manage and control access to mainstream British society also provides a valuable framework for understanding how some minority groups attempt to uphold a sense of ethnic identity (Harvey, 2001). As such, it is argued that examining how illness, disability and care are perceived by Britain's minority ethnic and religious groups may provide an additional explanation for how British health and social services are systematically accepted and rejected.

### **2.3.1 EXPLORING CARE WITHIN THE CONTEXT OF THE FAMILY, GENDER, ETHNICITY AND RELIGION**

Here, the sociology of care is reviewed, with a specific focus on informal family care. In keeping with the research aims, the subsection focuses specifically on the intersections of care with gender, ethnicity and religion. Phillips (2007) argues that defining care can be a contentious issue, especially as popular discourses surrounding terms such as 'informal' and 'formal' may be negatively interpreted by some, as for 'carers and care recipients who plan and organize their care routines and patterns; there is nothing necessarily informal about many of these arrangements' (p.23). Nevertheless, she argues that the main distinction between types of caring is between formal and informal. She defines formal care as that which is paid, regulated and monitored. She goes on to argue that informal care is usually unpaid, associated with the family (family care), carried out within the home, unregulated, and unmonitored (also see Graham, 1999). Phillips (2007) contribution usefully explains how the terms 'informal care' and 'family care' are often used interchangeably within discourses surrounding the patterns of caregiving within the family.

A further distinction important to acknowledge within debates on care is between 'caring for' and 'caring about'. Cronqvist *et al.* (2004) provide an illuminating discussion of the definition of 'caring for' and 'caring about'. They argue that 'caring for' refers to the task oriented labour carried out by carers. It may be understood as the moral obligation to

fulfil caring obligations and responsibilities, and refers to the practical, routine and technical aspects of performing care. Conversely, Cronqvist *et al.* (2004: 68) define 'caring about' as the inherently moral obligation, which 'assumes a personal ability to know what is morally good to do in a caring situation'. It implies a genuine concern about the well-being of the cared for person. 'Caring about' highlights the emotional aspects of giving care, which may include, genuineness, feelings, intuition, beliefs and personal values (Cronqvist *et al.*, 2004). Grant (2004) argues that the delivery of care continues to be based on the assumption that 'caring about' someone naturally leads to 'caring for' someone. She argues that providing care is a complex and highly variable undertaking, which requires further research if we are to challenge these types of assumptions.

The conceptual framework that the 'caring for/caring about' distinction provides, enhances an understanding of the complexity surrounding defining care and distinguishing between types of care (Graham, 1983; James, 1992; Lynch, 2007; Phillips, 2007). For example, a nurse may be expected to simply 'care for' her patients, by performing routine and technical tasks, however, there may be additional emotional factors that compel her to 'care about' her patients, whereby she utilises her intuition and feelings to guide her in her caring role (see van Schie and Seedhouse (1997) for a detailed discussion of this). In this way, she may argue that her emotions, intuition and feelings associated with 'caring about' her patients enhance her ability to perform the

instrumental or technical aspects of her professional role ('caring for'). On the other hand, a daughter may have a moral obligation to provide care for an elderly father-in-law, however, she performs this role against her wishes, which results in the daughter providing 'care for' him in terms of the practical caring tasks, without actually 'caring about' her father-in-law, or having an emotional investment in his well-being. In this way, acknowledging the distinction between 'caring for' and 'caring about' allows for a more in-depth understanding of how care is performed in both formal and informal settings. These debates provide context for the ensuing discussion.

Over the last twenty years there has been a highlighted interest in caregiving from 'policy makers, professionals and academics' (Phillips, 2007: 2). This seems to have stemmed from two interrelated factors. First, researchers such as Nolan *et al.* (1991) have argued that chronic illness currently represents the biggest challenge to British state health and social services. This is due to the advances in disease prevention and the consequential increase in life expectancy (Bury, 1997). In addition to this, fertility rates are decreasing (Charles and Sevak, 2005), resulting in an ageing population more at risk of chronic illness and requiring full time care. Second, the accentuated need for care has placed a spotlight on the informal care that is being carried out. Biegel *et al.* (1991: 7) argue that '[i]nformal service providers, like the family, have always been the primary source of human service care to individuals in need. In fact, if such informal service providers were

unavailable, professional agencies would be so inundated with service demands they could not function'. Although existing literature acknowledges the important role that informal carers carry out, much of this body of literature also criticises health and social services for failing to adequately support carers, which continues to relegate carers into the private sphere. This is examined below.

Many researchers suggest that family carers have inadequately received the implementation of policies within the health sector designed to aid people with chronic illnesses and disabilities. Twigg and Atkin's (1994) research revealed that GPs and hospital consultants were often unaware of the existence of family carers. This resulted in increased pressure on community nurses to provide information and support. Due to the demands of the occupation however, resources tended to be limited to those vocal and eloquent enough to request support. Twigg and Atkin's findings have been supported by a wealth of current research calling for increased emotional and economic support for family carers (Lobchuk and Vorauer, 2003; Kirk *et al.* 2004; Parish *et al.* 2005). Additionally, requests for professionals to understand the psychological aspects of family caring including the quality of life of both the caregiver and care receiver are increasingly prevalent within academic research (Myaskovsky *et al.*, 2005; Twigg and Atkin, 1994). Understanding the psychological aspects of caring and being cared for seems to have received relatively little attention within the sociological study of care.



Lynch's (2007) work on 'love labour' provides an important contribution to this underdeveloped aspect of care knowledge. She begins by challenging the assumption that professional agencies can offer primary care on a paid basis. She argues:

It is constitutionally impossible to offer primary care on a paid basis as, by its very nature, the love labouring that is involved in producing it is person-specific and is set within the context of pre-established relationships of trust; it has an assumed future involving continuity and attachment (p.563).

Lynch (2007: 550) utilises the term 'love labour' to describe the caring acts that cannot be commodified or paid for. To further examine 'love labour', she locates it within a 'three fold taxonomy for analysing other-centred work'. This distinguishes between primary care relations (love labour), secondary care relations (general care work) and tertiary care relations (solidarity work). Lynch argues that love and nurturing are essential to human development and existence. In this way, intimate caring relationships require a 'labour of love', which is 'undertaken through affection, commitment, attentiveness and the material investment of time, energy and resources' (p.557). She goes on to describe how the person who has primary care over a vulnerable other is required to carry in their minds at all times a 'care map'. This map requires overseeing and implementing in terms of its scope and quality throughout the care journey (p.559). Lynch's work draws attention to the

multifaceted nature of care work, especially when it takes love labouring forms. She argues:

What is clear from the work of care researchers is that care work generally involves not only *emotional work* and *moral commitment*, but also *mental work* (including a considerable amount of planning), *physical work* (doing physical tasks including body work such as cleaning, lifting, touching and massaging) and *cognitive work* (using the skills of knowing how to care). (Original emphasis, p. 557).

Lynch (2007: 551) argues that insufficient attention has been given to love and care, which have been treated as private and personal matters, without being given significant importance in theory or empirical research. Her work champions the invaluable distinct and 'non-commodifiable' labour that carers undertake. Additionally, the paper highlights the complexities surrounding the subjective and intimate experiences of care work and draws attention to the ways in which gender, social class and migration interface with care commanding. Furthermore, Lynch points out the complexities that exist within these groups arguing that 'although women are generally more likely to be morally compelled to undertake love labouring work [...] there are differences between women; sometimes family care is organised in highly individualised agreements between family members and/or between the carer and care recipients' (p.560). Exploring the gendered nature of care, as Lynch suggests is of particular importance to understanding the intimate and intricate complexities of undertaking

care work.

The 2001 National Census, though rather dated, presents one of the most up to date national figures on the gendered division of care. Using data from the Census, the Office for National Statistics (2004) report: '[i]n April 2001 there were 5.9 million informal carers in the United Kingdom. The majority of these carers were female (3.4 million compared with 2.5 million males)'. Gender and care has been a central focus of the feminist debate on the patriarchal nature of the family (e.g. Dressel and Clark, 1990; Oakley, 1974). Feminist theorists have argued that public policy assumed women had a duty to provide unpaid informal care (Powell, 1989). Thus, policy makers have regarded women as a reserve army of unpaid labour (Dalley, 1996). These arguments were briefly challenged when the 1985 General Household Survey exposed an unexpectedly high number of male carers. Further investigation into these figures, however, revealed that the majority of male carers were caring for a spouse and tended to exclude caring for long hours and carrying out intimate tasks (Dalley, 1996). Arber and Ginn (1999) produced similar findings in their study on the gendered nature of informal care. They argued that men were less likely to provide care for someone in another household, and less likely to perform intimate tasks. However, their research also pointed to certain cross-sex taboos, whereby it was generally preferred if intimate care work was carried out with carers of the same sex. Consequently, they point to the fact that the majority of elderly people requiring care are

women. Although the outcomes of these debates ultimately renounced the claim that men carry out a significantly large amount of care, it draws further significance to the complex nature of how care is divided, allocated and supported within informal networks such as the family.

Finch and Mason (1993) draw specific attention to the negotiation of family responsibilities. Within this, they argue that 'it is important to understand the ways in which people get locked into developing commitments, and how these vary for men and women' (p. 120). They conclude by arguing that the relationship between gender and the ability to make legitimate excuses for care is complex. In this way, they argue that the ability to get an excuse accepted is much more to do with 'understanding how commitments and reputations developed over time, and how women and men, or different categories of kin, are likely to be differentially positioned within this' (p.125). Some scholars have observed this negotiation of responsibilities as a 'hierarchy of care' (Lewis and Meredith, 1988; Punch, 2001; Silva, 2005), which is almost solely gendered, but also may be dependent upon 'perceived priority role of certain members, proximity, marital status, other caring responsibilities and mutual affection' (Phillips, 2007: 63).

Phillips (2007) presents a more up-to-date theoretical debate of the inextricable link between care and gender. She argues that policy has hinged on the traditional biological determinism of women carrying out private domestic roles and men dominating the public arena of work as

family breadwinners (see also Parton, 2003). She points out that this model may be outdated for application in modern society and calls for a 'repackaging of the concept of care based on a 'feminist ethic of care'' (p. 74). Maeckelberghe (2004) defines care ethics as taking the central activity of caring seriously. She argues that it is feminist because it disputes the assumption that caring is a requirement of women over men. Phillips (2007: 82) argues that the feminist ethic of care moves beyond dichotomies of public/private, male/female, and carer/cared for. It calls for care to be understood as being complex and multifaceted. Features of the model include that caring should be a valued human practice; that caring is central to human life; that there are different perspectives of care receivers, caregivers and policy makers that need to be taken into account; and that difference and diversity should be embraced.

Parton (2003) explores these debates further by arguing that a feminist ethic of care sees emotions as central to an adequate account of human rationality rather than being in opposition to it. Moreover, he asserts that care should be acknowledged as central to everyone, not only women. Care-receiving highlights human vulnerability, not just the vulnerability of children and elders, but as something we all experience at different times in our lives. James (1992) echoes these perspectives in her work on 'emotional labour', which she identifies as a key factor in domestic and workplace care work, but which is often invisible. She defines emotional labour as 'about action and reaction, doing and

being, and can be demanding and skilled work. The labourer is expected to respond to another person in a way which is personal to both of them but like other aspects of care it develops from the social relations of carer and cared-for and is shaped by the labour process' (p.500). The value that James places on emotional labour leads her to argue that it not only requires increased recognition as a component of care, but it requires building upon within the health care systems.

Phillip's (2007) and Parton's (2003) support of the 'feminist ethic of care' removes essentialist assumptions that care will necessarily be carried out by women, or that women necessarily share the same experiences of caring. Indeed, research suggests that the intersections of gender and ethnicity possibly produce diverse experiences of care. This is discussed in more detail below.

As discussed in Chapter One, statistics provided by the 2001 National Census led Young *et al.* (2005) to observe that Bangladeshi and Pakistani men and women are more likely to carry out care than any other ethnic group in Britain. Furthermore, they point out that women from ethnic minority groups are more likely to undertake caring roles than men. These findings highlight the diversity of the caring experience based on the situational and interrelating factors including gender, ethnicity, geographical location and class.

Research on the ethnic experiences of care have largely focused on

perceptions and experiences of accessing public services, rather than examining the private aspects of carrying out care on a day-to-day basis, or undertaking 'love labour' (Lynch, 2007). For example, Katbamna *et al.* (2004) argue that South Asian carers are prevented from accessing health and social services due to:

...the inability of services to meet the needs of users who speak languages other than English, forms of service provision which are culturally inappropriate or inflexible, and additional barriers among service providers which run from a lack of understanding to racism (p. 405).

This indicates a failure of service providers to supply appropriate provisions for ethnic family carers. Katbamna *et al.*'s (2004) research provides a particularly salient contribution to policy research, however, there continues to be a gap in knowledge about how care is experienced, perceived, allocated and divided within ethnic minority groups (Mak, 2005). Atkin *et al.* (2002) touch on some of these issues in their study of young South Asian deaf people and their families. Their research revealed that families often felt threatened when their deaf relatives attended clubs specifically for deaf people, as they feared it might undermine other identities such as their native language or religion. For many ethnic minorities in Britain, religion is an important aspect of their identity. Adamson and Donovan (2005) argue that this can be reflected in the caring and coping strategies of those caring for family members. As my research specifically addresses Islam, the

remainder of this section will examine the current literature on Islam and care.

It is widely acknowledged that the family plays a crucial role within Islamic discourse (Ansari, 2004; Basit, 1997; Dhami and Sheikh, 2000). Women are central within this, especially as some popular Muslim understandings of gender assumes traditional roles whereby men are expected to provide for the family financially, and women are responsible for undertaking the caring roles of 'home-maker' (Rippin, 2001). This has traditionally resulted in Muslim women predominantly occupying the private, domestic sphere. These traditional Islamic notions of gender are being challenged by many Muslim women (Brown, 2006; Ramji, 2007), especially in Britain (Ansari, 2004), however, research suggests that many Muslim women continue to perceive their domestic role as a religious obligation.

The anthropological contributions of Gardner (2002) in her study of the transnational relationships between residents of Britain and Bangladesh provide further knowledge to debates around Islam, gender, disability, and care. The participants in her research often described their roles as carers and mothers to be of spiritual significance, whereby the notion of 'being a good woman' was inseparable from being an unquestioning provider of care for one's husband, children and elderly relatives, whatever the circumstances. This in turn is related to religiosity and ones relationship with God' (p.130-131). As such, the women in



Gardner's (2002) study were often the sole providers of care. These gendered findings were particularly significant for the Bangladeshi migrants to Britain. Here, relatives who would ordinarily contribute to the care of a family member often remained in Bangladesh, leaving women without a network of support for their caring role. Furthermore, the demanding nature of providing care for a relative often meant that carers were unable to spend time learning the language, which exacerbated a sense of isolation. Gardner (2002) goes on to suggest that these structural factors may contribute to the particularly gendered nature of providing care for Bangladeshi migrants in Britain.

Such anthropological and ethnographic contributions have also been addressed within an international context and provide important knowledge about the link between Islam, gender, disability and care. For example, Atshan (1997) focuses on disability within Palestine, arguing that due to the number of soldiers disabled in conflict with Israel, some positive attitudinal changes have taken place at a societal level towards disability, however disability discrimination continues. Moreover, the stigma and shame of a family member with disabilities impacts upon the honour of the entire family. However, the social consequences of a disabled family member are heavily gendered. Ashtan (1997) argues:

While male children have economic significance within the family, female children carry a symbolic value; this is in line with the fact that women are, in many cultures viewed as symbols of worth and honour.

The health and beauty of girls and women are a representation of well-being, and a symbol of good standing of the family (p. 54).

In light of these findings, disabled women and women within families with a disabled relative often find themselves unable to marry due to the perception that the condition may be genetically passed on through the generations or potentially contagious.

Ashencaen Crabtree's (2007a) work on parents caring for children with developmental delays in the United Arab Emirates echo these findings. In particular, she discusses the consequences on the Mother of bearing a child with disabilities. She argues that divorce and polygamy are often used as weapons against women with childbearing issues. As a consequence, acceptance of a child with disabilities was of particular importance to the mothers in her study. Like the participants in Gardener's (2002) study, Ashencaen Crabtree's (2007a) respondents reported that mothers also tended to be the primary caregivers and that the performance of care was heavily gendered. In addition to these findings, she explores the spiritual beliefs of her participants, arguing that although some perceive the birth of a disabled as a punishment from *Allah*, in the main, it was regarded as being part of a divine plan which will award blessings upon the family home.

Similarly, Ahmed and Rees Jones (2008) in their study of female Bangladeshi carers in London reported that '[m]ost of the respondents expressed a strong sense of duty to provide the care. This sense of

duty derived from strong religious (Islamic) beliefs and seemed to place constraints on seeking outside support' (p.66). Ahmed and Rees Jones's (2008) findings provide an important contribution to knowledge about how traditional gender roles are informed by religion. Furthermore, their study highlights how religious belief can inform the 'care map' (Lynch, 2007) that a carer keeps in their mind and shapes the decision making processes such as seeking outside support. The following sub-section examines in more detail how ethnicity and faith may impact on how services are managed, controlled and experienced.

### **2.3.2 EXPLORING THE DIVERSE EXPERIENCES OF ILLNESS AND DISABILITY**

This sub-section examines the argument that current sociological understandings of illness and disability fail to account for the diversity of experience between ethnic and religious groups in Britain. It uses existing literature to argue that experiences of illness and disability are culturally and religiously specific. Furthermore, these diverse beliefs may be at times incompatible with western medical beliefs espoused by health and social services. These arguments are particularly pertinent to research on care as it is possible that diverse perceptions and experiences of health and illness at the intersections of ethnicity and religiosity may shape how the performance of care is undertaken.

In a study carried out to mark the silver anniversary of the leading academic journal *Sociology of Health and Illness*, Armstrong (2003)

noted that themes such as the theoretical constructs for the field and issues of identity were particularly prevalent within the articles. This finding is significant when considering the societal changes that have taken place in the last twenty-five years. An increase in disease and infection prevention, combined with falling death and fertility rates has resulted in an ageing population more at risk of chronic illness and disability. Additionally, globalisation and improved mobility has led to increased cultural diversity within Britain. Consequently, some researchers have argued that classical theoretical understandings of health and illness are dated and need to account for societal changes. Adhering to this viewpoint, Kelly and Field (1998) argue that:

[N]ot only have the social structures of contemporary western societies become more diffuse and fragmented but the experiences of chronic illness have also become more diverse (p. 11).

Kelly and Field (1998) present contemporary society as rapidly changing and unstable. They argue that a current theoretical assumption of health and illness needs to be inclusive of these factors. Arguably, experiences of illness and disability will depend, at least in part on culture and identity. House (2002: 134) argues that racial-ethnic status has an important influence on 'exposure to and experience of virtually all known psychosocial, and biomedical, risk factors of health'.

In a classic study of patient symptoms and complaints, Zola (1966) argued that experience of illness and pain is variable and dependent on

social factors such as gender and ethnicity. In his study, Zola found that when comparing Italian and Irish patients in an outpatient clinic:

Not only did the Irish more often than the Italians deny that pain was a feature of their illness but this difference held even for those patients with the same disorder (p. 623).

In conclusion Zola called for a re-examination of 'rigid' definitions of health, illness, normality and abnormality implemented by official treatment agencies (p.630). Supporting Zola's findings, Turner (2001) points out that illness behaviour can be culturally specific:

[I]n the Islamic Middle East illness behaviour can be a method for legitimating behaviour which deviates from conventional societal expectations [...] A woman who is sick by possession may reject the offer of marriage selected by her father(p. 52).

As such, experiences of illness and disability can be shaped by cultural and religious factors. Without an understanding of these factors, healthcare services may not be able to sufficiently account for groups of people who do not adhere to western medical beliefs about health, illness and disability. Avoidance of medical services by Asian communities has also been explained by differences in cultural and religious beliefs about medication. Horne *et al.* (2004) found that negative perceptions of medication and a resistance to being prescribed medication were more likely in Asian individuals in the study. In

conclusion they insist that variables such as household composition, generation and religion must be further investigated and its findings used to 'improve the delivery of care' (p.1312).

Existing literature suggests that ethnic minorities have also experienced cultural intolerance and misunderstanding within the healthcare system. In an ethnographic study of midwives, Bowler (1993) identifies four racial stereotypes that the midwives upheld when treating women descending from South Asia. These stereotypes were distinctly negative, and included the view that such women abused health care services, lacked a 'normal maternal instinct' and were difficult to communicate with due to language barriers (p.157). Referring specifically to chronic illness and disability, research has tended to suggest that discrimination and disadvantage are reinforced if the person is black or of South Asian descent (Ali *et al.*, 2001). Such barriers have wide implications on an individual's life including an unwillingness to interact with health care services (Ahmad *et al.* 2000, cited in Ali *et al.*, 2001). In addition to this, integration into British society for some disabled ethnic individuals including refugees and asylum seekers is virtually impossible as forced dependency and inaccessible buildings renders the individual immobile (Harris, 2003).

Cultural and religious differences in how illness and disability is experienced, perceived and understood provide a valuable insight into how services may be accessed or not accessed by minority ethnic and

religious groups. Furthermore, external barriers such as institutional racism, language barriers and religious and cultural insensitivities may also reinforce a separation between Britain's minority communities and access to health and social services.

The following sub-section further examines access to mainstream British services by ethnic groups from the perspective of upholding ethnic and religious identities.

### **2.3.3 PURITY AND POLLUTION: QUESTIONING THE POTENTIAL MOCHADI FOR MUSLIMS IN BRITAIN**

Research on the British Muslim experience of accessing health and social services is limited. Of the literature that is available, most agree that this process is somewhat problematic (Atkin *et al.*, 2002; Hussain, 2005; Katbamna *et al.*, 2004). This may be explained in part by institutional barriers that prevent many of Britain's minority ethnic and religious communities from accessing certain citizenship rights, however, these conclusions are somewhat tentative due to the limited literature on the subject. Furthermore, to argue that such access issues are solely an institutional issue renders Britain's Muslim communities devoid of autonomy or agency. Although I present the link between the experiences of Muslim family carers and Traveller-Gypsies tentatively, Judith Okely (1983), in her anthropological study, presents her sample of *The Traveller-Gypsies* as active participants in their segregation from many aspects of British social life. Contrary to the common assumption

that a dominant group will 'rub off' (1983: 77) on a subordinate group, Okely argues that the Gypsies provide an example of an ethnic group that has changed and adapted on their own terms. In this way, the Gypsies have been able to incorporate aspects of mainstream society whilst retaining a strong ethnic identity.

Similarly to British Muslim communities, Okely (1983) argues that the Traveller-Gypsies have also received substantial negative attention from wider society. Additionally, constant pressure from non-Gypsies or '*Gorgios*' to assimilate and reject key aspects of their identity such as living in a caravan resonates with pressure applied to Muslim communities to cast off religious symbols such as a woman's choice to wear the veil (Ezekiel, 2006). Okely (1983) argues that one way of upholding a minority identity is by employing pollution beliefs that serve to express and reinforce the symbolic boundary between the ethnic group and mainstream society. *Gorgio*'s are therefore regarded as being polluted or *mochadi*, and contact with non-Gypsies is controlled and restricted. Thus, the Gypsies adhere to strict rituals concerning cleanliness and contamination that relates to inner/outer body symbolism. The outer body represents the polluted, therefore, skin with its 'discarded scales' (Okely, 1983: 80), the by-products of hair, and faeces are all polluting if entered into the inner body. In this way, anything entering into the inner body must be ritually clean. Not only food, but receptacles of food and anything placed between the lips. Okely (1983) interprets these rituals as being symbolic of the Gypsy's



ethnic separateness from non-Gypsy society. Here, the outer body represents the self or role as presented to the *Gorgio*. This outer self must protect the purity of the inner self from the potential pollution inflicted by the non-Gypsy. Okely (1983) argues that:

The Gypsies beliefs cannot be seen independently of those of the larger society, mainly because they create and express symbolic boundaries between minority and majority. The beliefs are allied to daily, often commonplace practices concerned, for example, with eating, washing, the use of space and the placing of objects in that space (p. 78).

Research on the symbolic boundaries imposed by British Muslim groups to retain a sense of ethnic and religious identity remains relatively underdeveloped, especially with how entry into mainstream society is negotiated. There is some evidence to suggest that 'religious identification is heightened as a form of cultural defence in a religiously and ethnically different society' (Yip, 2004: 338). Cooke (2007) refers to what she terms as the 'Muslimwoman' to describe the entwining of gender and religion and the 'erasure of diversity' (p. 139) for Muslim women in contemporary society. She argues that in the aftermath of 9/11 religion and gender were collapsed into an essentialist singular identity, 'Muslimwoman', which was imposed by both non-Muslims and Muslim religious extremists (Cooke, 2008). Cooke (2007) describes how Muslim women have come to define the boundary between the pure and the impure. In this way, Muslim women are potentially

*outsiders* that *insiders* must protect from being polluted in order to uphold the purity of the *inside*. She argues:

Muslimwoman locates a boundary between “us” and “them” and signals Muslim women’s interstitial outsider/ insider status. As women, Muslim women are outsider/ insiders within Muslim communities where, to belong, their identity is increasingly tied to the idea of the veil. As Muslims, they are negotiating cultural outsider/insider roles in societies where Muslims form a minority or they are under threat (2007: 140).

Cooke’s arguments are consistent with Okely’s (1983) observations of the Traveller-Gypsies in that it touches on the bodily symbols and purity rules employed by certain minority groups to uphold a sense of ethnic identity. Available literature detailing the improvements needed at an institutional level to include Britain’s minority citizens provides an invaluable addition to knowledge. However, developing the literature on how minority communities attempt to uphold religious and ethnic identities may provide additional knowledge on how Britain’s ethnic groups negotiate access into mainstream British society. This goes beyond simply calling for increased provisions for minority service users, as much of the literature on minority carers tends to suggest. Ahmed and Rees Jones’s (2008) study of female Bangladeshi carers adheres to these perspectives. Although the findings of their research confirms the calls of other researchers for increased provisions for minority ethnic carers, they argue that ‘where there is evidence of a lack

of agency and resistance to support services, the explanation for this needs to move beyond poor information and language issues' (p.73).

This sub-section examines how minority groups may attempt to remain separate from some aspects of mainstream society in an attempt to retain a sense of ethnic identity. These perspectives provide an important basis within which to understand how minority groups access health and social services, however, these issues have received little attention within academic literature.

#### **2.3.4 SUMMARY**

This section explored the factors surrounding the undertaking, or performance of family care. As such, it firstly examined the sociology of care. This observed how previous studies have revealed that family carers continue to play an indispensable yet rather invisible role within society. Data from the 2001 National Census provides support for the theoretical discussions surrounding the inextricable link between gender and care, showing that women continue to be more likely to undertake the majority of informal care. This led to a discussion of existing literature on the care, ethnicity and religion, with a specific focus on South Asian and Muslim carers.

The following subsection examined how cultural and religious differences in the perceptions of illness and disability, provides a valuable insight into how services may be accessed or not accessed by

minority ethnic and religious groups. Institutional racism, language barriers and religious and cultural insensitivities may also reinforce a separation between Britain's minority communities and access to health and social services. This is discussed below.

The final section predominantly focused on Okely's (1983) theories of how certain minority groups uphold aspects of their ethnic identity employing pollution beliefs about mainstream society. Although her perspectives are based on a very different minority group (Traveller-Gypsies), she regards her observations to be applicable to other ethnic groups. Her theories shape a potentially interesting gap in knowledge pertaining to how Muslim family carers manage and control access to secular British society.

The networks and kinship groups to which a Muslim family carer belongs may also shape the experiences of accessing services. Consequently, the following section employs the concept of social capital to frame how these experiences may be explored and understood.

## **2.4 NEGOTIATING FAMILIES, TIES AND KINSHIP GROUPS: EMPLOYING SOCIAL CAPITAL TO CONTEXTUALISE THE EXPERIENCE OF CAREGIVING**

As Britain's multicultural communities increase, the concept of social capital is experiencing a revival as a conceptual tool for analysing

families, ties, kinship groups, networks and communities (Field, 2003; Fine, 2010; Halpern, 2005). As the ensuing section will explore, social capital allows us to understand how ties and networks can be supportive, helpful and even emancipatory, whereas others can prevent and inhibit access to the resources and support of the group (Anthias, 2007; Crozier and Davis, 2006; Edwards, 2004; Zontini, 2006; 2010). This is of particular value when researching minority, marginalised, vulnerable, or disadvantaged groups, whose access to support from the family, community or society may be complex. In terms of its application to my research, social capital is a useful concept for exploring how the Muslim family carers in the study are supported and inhibited by their membership to certain networks such as the family, communities, and formal support organisations (this is explored in Chapter Six). Although there is significant controversy surrounding the definition of social capital (see Fine, 2010 for a detailed discussion of this. Additionally, see Goulbourne and Solomos, 2003; Portes, 1998; 2000), most definitions tend to share a core idea that:

[S]ocial networks have value. Just as a screwdriver (physical capital) or a college education (human capital) can increase productivity (both individual and collective), so too social contacts affect the productivity of individuals and groups (Putnam, 2000: 19).

This section critically examines the emergence of the concept of social capital by examining in turn the contributions of the three most readily cited proponents of social capital; Pierre Bourdieu, James Coleman,

and Robert Putnam. The focus of discussion will then move to exploring how the concept has been usefully applied to both theoretical discussions and empirical research.

#### **2.4.1 THE EMERGENCE OF SOCIAL CAPITAL AS A CONCEPT FOR UNDERSTANDING RELATIONSHIPS WITHIN AND BETWEEN GROUPS**

Until relatively recently, Bourdieu's contribution to the concept of social capital has remained relatively overlooked (Fine, 2010), however, his work in this area is experiencing a revival in studies exploring marginalised and disadvantaged groups. This is primarily due to Bourdieu's interest in how the different forms of capital that he defined could be combined to create and reproduce inequality (Fine, 2010). Bourdieu (1992: 119) argues that 'capital presents itself under three fundamental species (each with its own subtypes), namely economic capital, cultural capital, and social capital'. He also adds symbolic capital, which he describes as being 'the form that the various species of capital assume when they are perceived and recognised as being legitimate' (Bourdieu, 1989: 17). In other words, the holder of symbolic capital is able to alter the actions of someone who holds less through the unspoken recognition of the power dynamics within the relationship. An example of this could be when a wife decides to go out with her friends in an outfit that her husband thinks is inappropriate. She may be met with disapproving looks and negative comments. These actions saliently communicate the message that the wife should change her clothing before going out with her friends, without the husband needing

to explicitly state the message. In this situation the wife has accepted that her husband has acquired a superior amount of symbolic capital and will therefore feel a duty to change her clothes, regardless of how the outfit actually looks. In this way, the wife is complicit in her own subordination because she legitimates her husbands' power over her decisions.

Bourdieu regarded economic capital as being of primary importance (Field, 2003; Siisiäinen, 2000). He defined it as being that 'which is immediately and directly convertible into money and may be institutionalized in the form of property rights' (1986: 47). Bourdieu does not award the same amount of attention to economic capital as he does to other forms of capital, arguing that '[a]s regards economic capital, I leave that to others; it's not my area. What concerns me is what is abandoned by others' (1984: 32).

Cultural capital refers to the way in which groups award status to some types of cultural tastes over others (Field, 2003). Bourdieu (1986) argues that cultural capital exists in three forms. Firstly, it exists in the 'embodied state', which refers to the socialized state of the mind and body. Secondly, it exists in the 'objectified state', which refers to cultural goods such as pictures, books and machines. Thirdly, it exists in the 'institutionalized state' or cultural institutions and is expressed in items such as certificates and qualifications (Siisiäinen, 2000). Lamont and Lareau (1988: 153) argue that the term has been operationalised as

both knowledge of high culture and educational attainment, and the capacity to perform tasks in a culturally acceptable way.

Finally, Bourdieu defined social capital as 'membership in a group – which provides each of its members with the backing of the collectively-owned capital' (1986: 51). He goes on to explain how actors mobilise social capital:

The volume of social capital possessed by a given agent thus depends on the size of the network of connections he can effectively mobilize and on the volume of the capital (economic, cultural or symbolic) possessed in his own right by each of those to whom he is connected' (Bourdieu, 1986: 51).

Bourdieu was interested in how the different forms of capital he defined could be combined to create and reproduce inequality (Fine, 2010), thus extending the definition of 'capital' to include aspects of capital other than the purely economic (Field, 2003). Through this view of capital, Bourdieu was able to perceive how capital could be mobilised by disadvantaged groups as well as advantaged groups. This has become a major advantage of Bourdieu's contribution to the concept of social capital, as it allows for both marginalised and privileged groups to be explored.

James Coleman contributions to social capital were primarily concerned with 'rational choice theory'. Zey (1998: 2) describes how this



perspective views action as only being taken after 'its benefits and costs have been weighed'. Moreover, humans will choose an action that yields the highest net benefit to the individual. Proponents of this theory, therefore, regard all action to be driven by self-gain. Coleman's work highlighted the importance of both the family and the community for assisting and preventing access to social capital. Coleman (1988: 98) regarded social capital as being a resource for rational action arguing that: '[i]f we begin with a theory of rational action , in which each actor has control over certain resources and interests in certain resources and events, then social capital constitutes a certain type of resource available to an actor'. He subsequently defines social capital as:

[D]efined by its function. It is not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors – whether persons or corporate actors – within that structure. Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible (1988: 98).

In contrast to Bourdieu's treatment of social capital as reproducing power, for Coleman, 'social capital helps to explain performance in educational achievement according to family and neighbourhood characteristics' (Fine, 2010: 40). As such, Coleman was interested in examining social capital from inside and outside the family, and its impact on the educational achievement of young people. He concluded

his study by arguing that '[t]he social capital of the family is the relations between children and parents [...] That is, if the human capital possessed by the parents is not complemented by social capital embodied in family relations, it is irrelevant to the child's educational growth' (1988: 110). Furthermore, Coleman (1988) argued that 'community' was an important factor in the educational achievements of young people.

Using empirical research to support his arguments, Coleman argued that high social capital was found in the 'religiously based private high schools' in his study, where the religious community surrounds the organisation and involvement from the family is high. In contrast he argued that low social capital was found in the 'independent private schools' in his study. Here, there is little sense of community and the families have little contact with the school. Consequently, Coleman argued that social capital was an important factor in the cognitive development of social actors. Similar to Putnam (see below), Coleman believed that social capital was essential to a functional society, however, he has been criticised for overstating the positive effects of social capital, and failing to acknowledge the 'dark side', or negative effects of social capital (Field, 2003). Unlike Bourdieu who regarded social capital as reproducing inequality, Coleman regarded it as being 'public good' (Portes, 1998).

Robert Putnam has become synonymous with the concept of social capital (Halpern, 2005). His book, *Bowling Alone* (2000) became a national bestseller and consolidated a message that he had been developing throughout the 1990s: America was experiencing a decline in social capital, which, in his view, explained why certain urban areas were 'ungovernable' (Field, 2003). Putnam largely accuses the increase in television consumption to be at the root of the decline in social capital in America. His theories are based in part on earlier research carried out in Italy (see Helliwell and Putnam, 1995). The study compared different regions of Italy in an attempt to explain why some regional governments were more effective than others. It concluded by arguing that regional government's effectiveness was not explained by economic factors such as the size of their budgets, but was based on the 'vibrancy of associational life and the level of trust between strangers inside their regions' (Halpern, 2005: 8).

On the cover of the book *Bowling Alone*, Putnam (2000) uses an illustration of a lone bowler to convey his message that America's communities are in decline. Putnam himself used to compete in bowling leagues and uses his experience to argue that individuals are more likely to compete with close friends and family rather than take part in bowling leagues, which would enable interactions with other members of society. The simplicity of this metaphor may also act as a metaphor for some of the criticisms levelled at Putnam. These criticisms include questioning Putnam's assertion that America's communities are in

decline and suggesting that they may instead be changing (Portes, 1998), and that he fails to account for technological advances in communication including internet networking (Field, 2003). Fine (2010) argues that Putnam fails to acknowledge some of the fundamental historical contributions to the social capital debate including the important theories of Coleman and Bourdieu.

Regardless of the numerous criticisms of his work, Putnam contributes some interesting and useful theories of social capital, which continue to influence theorists and researchers. His work on *bridging* and *bonding* social capital has been particularly popular, however, he credits Gittel and Vidal (1998) for coining the terms. Bonding social capital refers to exclusive social networks, and focuses on the specific needs and interests of group members (Wuthnow, 2002). Examples include kinship ties such as family and friends, church based reading groups and membership to country clubs. Putnam (2000: 23) asserts 'Bonding social capital constitutes a kind of sociological superglue, whereas bridging social capital provides a sociological WD-40.' Bridging social capital refers to inclusive ties. Examples include 'the civil rights movement, many youth service groups, and ecumenical religious organizations' (Putnam, 2000: 22). Putnam describes these ties as being 'outward looking' and requires involvement with people across possible social divides. Cheong *et al.*, (2007: 29) argue that bridging social capital concerns 'horizontal ties based on common interests that transcend heterogeneous differences of ethnicity, religion and socio-

economic status'. These distinctions have allowed for more nuanced approaches to the study of social capital, particularly in health research (see Beaudoin, 2009; Poortinga, 2006).

#### **2.4.2 SOCIAL CAPITAL: CARE, ETHNICITY, AND RELIGION**

The above subsection provides a summary of three theorists that are widely acknowledged as being the most influential to the development of the concept of social capital. It also provides a basis for the ensuing discussion. Below, an analysis is presented of how the concept of social capital has been applied to modern sociological thought and to empirical research.

Choeng *et al.* (2007: 28) challenge the classical concepts of social capital described above by arguing that 'a focus on social capital assumes that everyone counts the same as everyone else without regard for the diversity of social context and economic inequalities'. Indeed, many modern social theorists have attempted to develop the concept of social capital to include the experiences of diverse social groups. Some have argued, however, that this has made the concept difficult to define (Takhar, 2006) and that its application has become too broad to contribute anything meaningful (see Anthias, 2007; Halpern, 2005; Fine, 2010). Nevertheless, Choeng *et al.* (2007) assert that since its application into mainstream policy discourse, social capital has been regarded as a positive resource for British society. From this perspective, they argue that social capital should be perceived as

socially constructed, and dependent upon the prevailing ideological and political climate.

Similarly to Choeng *et al.* (2007), Anthias (2007) criticises how popular discourse on the accumulation of social capital assumes that it creates social cohesion. In this way, she theoretically aligns herself more closely with Bourdieu, than with Coleman or Putnam. Her focus on ethnic ties for minority ethnic groups leads her to argue that 'we should confine the notion of social capital to mobilisable social ties and networks. In other words networks and ties which are not mobilisable for the pursuit of advantage, or the mitigation of disadvantage, are not usefully referred to as social capital' (p. 788). From this perspective, she criticises Coleman and Putnam for failing to acknowledge inequalities present within communities and networks, and the ways social capital may be unevenly distributed within and between social groups.

Anthias also challenges the rigidity of Putnam's 'bridging' and 'bonding' distinctions of social capital:

One major problem lies in denoting a fixed boundary between bonds existing within a group and bridges that exist between groups. The definitional elements here have the danger of becoming essentialist in as much as the boundaries between bonding and bridging may be flexible and changing, depending on the context and meaning. This is because there is always a problematic relating to what and who is in the group and who belongs and who doesn't belong to it (p.791).

Anthias continues to argue that resources require mobilising to be classified as social capital. For example, money may be a resource to buy food with, however, money is useless without the knowledge of where or how to buy food. As such, Anthias argues that resources must be mobilisable in two ways for it to be considered social capital. Firstly, there is the ability to mobilise one's advantaged position within a social network to further advance one's hierarchical position. For example, getting a promotion, making more money, accessing better housing, being in better school catchment areas, and so on. Anthias argues that this form of social capital consolidates an advantaged social position and excludes, curtails and limits the ability of others to access resources. The second form of social capital is 'negatively advantaged social capital' (p.794), which is mobilisable through coping strategies or 'defensively orientated' mobilisabilities. Individuals come from a starting point of disadvantage, but an orientation to defend and survive propels the individual to usurp and succeed. Anthias cites Archer and Francis's (2006) research as an example of this. Here, Chinese parents' preoccupation with escaping their own migrant hardship was focused on the economic potential of their children's education (cited in Anthias, 2007). Anthias's perspectives allude to the fluidity of social capital, and assert that its usefulness is dependent on identity, time and space.

By developing the concept of social capital to include the experiences of diverse groups, many researchers have perceived a gap in the existing knowledge on social capital, such as the experiences within the family

(Zontini, 2006; 2010) ethnic communities (Crozier and Davies, 2006), gender (Edwards, 2004), religion (Candland, 2000), disability (Looman, 2004), and the intersections that exist between groups. For example, Takhar (2006) explores the lives of South Asian women in minority ethnic communities by examining the tensions that exist between multiculturalism and social capital. She employs Kymlicka's (1995, cited in Takhar, 2006) distinction between two types of 'minority rights' to analyse South Asian women's rejection of multicultural citizenship as a model of emancipation. The first type is when minority group rights are promoted. Here, equality exists within and between groups (bonding and bridging social capital). The second type is where minority groups impose restrictions upon its own members based on traditional, religious, or cultural practices. Takhar describes the tensions associated with the second type:

Problems associated with the second type are toleration of diversity within the private sphere and a view of culture. Located within the private sphere is the family and the crucial point to consider is power inequalities, that is, who determines acceptable forms of femininity and behaviour. For South Asian women who choose to opt out of the traditions and practices of cultural groups, they often risk being ostracized by the family and the community (p.296).

Takhar continues by arguing that in connection with citizenship and minority rights, the state must ensure that there is cultural diversity,



however, it runs the risk of losing its reputation as a multicultural society if it intervenes in the domestic affairs of a minority group. As a solution to the problem she suggests that support be given to network groups who are involved in voluntary organisations. Consequently, challenges can be made to the culture from within the group. She cites evidence from her own research, including the Southall Black Sisters (1990, 2001, cited in Takhar, 2006) to support her claim and concludes that through the use of voluntary organisations, South Asian women can become empowered and develop different forms of capital. Moreover, her research reveals how social capital can be built in groups of people who are further marginalised in minority ethnic communities.

Marginalisation can take many forms. Some argue that family carers are among the most invisible minorities. Looman (2004) in her study of family caregivers of children with chronic conditions and social capital argues that despite the considerable literature on the health related benefits of informal community supports, relatively little literature has 'explored the specific social processes by which families manage resources for health' (p.413). Her research adopts a phenomenological approach to understanding how social capital was experienced by the families in her study. The data revealed some interesting findings about the nature of social capital for families caring for a child with a chronic condition. These included, among others, 'advocacy', which denoted a sense that a parent's experience of being a carer could help others. Also, belonging to a spiritual community brought a sense to many of the

carers in her study that 'an essential goodness exists within the world' (p.432).

### **2.4.3 SUMMARY**

Takhar (2006) and Looman's (2004) research highlights how social capital offers an interesting conceptual tool for understanding how marginalised and minority individuals mobilise the resources of the groups to which they belong (bonding social capital), and how they access resources outside of the group (bridging social capital). Much potential research in this area remains unaddressed, particularly with reference to caring within Muslim communities. This is particularly salient when considering how much existing literature reveals both the potential importance of faith as social capital (Candland, 2000), and the diverse experiences of social capital for minority ethnic communities (Anthias, 2007; Takhar, 2006; Crozier and Davies, 2006), and carers (Ahmed and Rees Jones, 2008; Looman, 2004).

## **2.5 CONCLUSION**

This literature review was framed by the research questions presented in Chapter One. From the discussions presented above, it is clear that there are many gaps in our understanding of Muslim family carers, making this an important topic for research. Moreover, how Muslim family carers perceive, perform and negotiate their caring role remains

largely unknown. It is clear from the literature that there are many accounts of South Asian carers, which at times include the voices of some Muslim participants. These sources tend to be brief, however, without a specific focus on Muslim carers, especially within sociological discourse. Nevertheless, existing literature suggests that Muslim carers may experience their identity in diverse and potentially interesting ways. This research intends to fill this gap in knowledge. The following chapter focuses on the methodological underpinnings that were employed to empirically undertake the research.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter provides an overview of the research process. I begin by exploring my social constructionist epistemological position, which fundamentally underpins the research design. This informs my choice of research method, and my decision to undertake semi-structured interviews with both Muslim family carers and professionals whose specific occupation relates to supporting Muslim family carers. An examination of how respondents were sampled and accessed precedes a section introducing the four carers' organisations from which the majority of respondents were sampled. A discussion of how the interviews were conducted, followed by an examination of the process of data analysis precedes an exploration of the ethical considerations of the study. A reflexive section then examines the location of the researcher within the field. Further to this, a specific section discusses the slightly different research techniques required to interview the professional respondents. The chapter finishes with a summary of the main points for consideration.

As the research design is constructed on the basis of the aims of the research questions originally introduced in Chapter One, they are

presented here to provide context to the ensuing discussions. This research is primarily concerned with answering the following overall thesis question: 'How do Muslim family carers of chronically ill or disabled family members perceive, perform and negotiate their caring role?' To fully explore this question, three research questions are posed:

1. In what ways do Muslim family carers of chronically ill or disabled relatives perceive their experiences to be informed by religious beliefs?
2. How do Muslim family carers of chronically ill or disabled relatives perceive, experience and negotiate health and social services?
3. How do Muslim family carers of chronically ill or disabled relatives experience and utilise both formal and informal support networks?

These questions are shaped by my social constructionist epistemological positioning. As such, the ensuing discussion introduces social constructionism and its application to this research.

### **3.2 EPISTEMOLOGICAL POSITIONING**

This research is underpinned by a social constructionist epistemology. Consequently, my focus is not concerned with discovering objective truths from my data. Instead, my focus lies with exploring the 'different

meanings with which our worlds become invested' (Burr, 1998: 13). Moreover, I am concerned with exploring how constructions of meaning are applied to the lived experiences of everyday life for the Muslim family carers in this study. This section explores these philosophical choices. As such, the section begins with exploring the definitions and applications of social constructionism. It then moves on to exploring the limitations and criticisms of constructionism, and how, in response to these challenges it has been usefully adapted and developed. The conclusion maps how this philosophical standpoint underpins this research.

Social constructionism as a philosophical standpoint has contributed much to existing literature, and continues to be applied by numerous disciplines to study human beings as 'social animals' (Burr, 2003). Some argue that this makes it difficult to define (Brown, 1995). Locke and Strong (2010) conceptualise social constructionism as a 'broad church', with 'some expansive tenets that hold it together' (p.6). Crotty (1998) argues that from a constructionist viewpoint:

Meaning does not inhere in the object, merely waiting for someone to come upon it...the world and objects in the world are indeterminate. They may be pregnant with potential meaning, but actual meaning emerges only when consciousness engages with them (p. 42-43).

Burr (2003: 2-5) defines four characteristics that a researcher usually adopts if they are to label themselves as a social constructionist.

1. A critical opinion of assumed or 'taken-for-granted' knowledge.
2. The ways in which aspects of the world are understood are culturally and historically specific.
3. Knowledge of the world is not derived from the 'real' nature of the world. Versions of knowledge are fabricated and constructed from the everyday social interactions between people.
4. Knowledge and social action are interrelated. What society 'knows' about something has an impact on how it is treated.

Much of the appeal of social constructionism is in its implicit anti-essentialism (Burr, 1998; Lock and Strong, 2010). In this way, Gergen (1999) notes how constructionist arguments invite moral and political deliberation, as they do not champion one idea over another.

Consequently, he argues that it offers 'a mandate for feminists, ethnic minorities, Marxists, gays and lesbians, the elderly, the poor and indeed all of us to challenge the "truth" and the "facts" of the dominant order' (Gergen, 1999: 231). Consequently, its application to political and moral debates, such as the disability movement, has been particularly effective. This is discussed in more detail below.

Classical sociological theory has tended to conceptualise chronic illness and disability as a 'problem' (Shakespeare, 1996). As such the

individual is responsible for 'normalising' herself or himself to fit into society and accept the limitations imposed by the impairment. This 'medical' model came under attack by the Disability Liberation Network that employed social constructionism to locate disability...

squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation (Oliver, 1996: p. 32).

These views formed the basis of the social model of disability, which has achieved much progress for the rights of people with chronic illnesses and disabilities. Recently, however the social model has been criticised for denying the personal experiences of disability by reducing it to mere construction. Handley (2003) cites the feminist slogan 'the personal is political' arguing that the social model simplifies disability, discounting for the complexity of individual experience. Whilst acknowledging the positive consequences of the existence of the social model, Gabel and Peters (2004) argue that a growing number of researchers are employing eclectic theories whilst identifying their work within the social model.

I identify with Gabel and Peters (2004) in that I also consider my research to be underpinned by an eclectic mix of social constructionist theories. When I consider the nature of my research, I find it difficult to



suggest that a mother caring for her child with severe physical disabilities is not faced with 'real' medical conditions. Such arguments, as Handley (2003) asserts, simplifies the complexity of the disabled experience and reduces medical conditions to mere construction. However, the ways in which the carer interprets the meanings of the medical condition of her child and her caring role within this is what is of interest and significance within this research.

Burr (1998) challenges both the proponents of social constructionism and its critics by asserting that its original meaning has been lost to dichotomous debates surrounding social constructionism (or relativism), and positivism (or realism). She argues that critics of constructionism seem to be 'contesting the idea that the world is a figment of our imaginations and has no materiality [...], which was never constructionism's claim (p. 23). Consequently, Burr (1998: 23) argues that debates need to transcend this misleading dichotomy 'so that we can talk of things being one and the same time socially constructed *and* real' (original emphasis). In this way, Burr (1998) encourages constructionists to go beyond being mere 'observers and commentators', and follow through with recommendations for change.

In response to the arguments proposed above, I assert my social constructionist stance with some caution. I acknowledge that there are certain areas where the application of social constructionism has been problematic (see Sayer, 1997 and Turner, 1996 for detailed discussions

of this), especially when it has historically resulted in core aspects of some people's identity being rendered as construction rather than a reality. Consequently, this research does not attempt to place emphasis on asserting what is "real" and what is "constructed". Moreover, the social constructionist approach here attempts to explore how meanings and understandings are constructed within the lived circumstances of everyday life.

Holstein and Miller (2007) describe the somewhat fitting term for this form of social constructionism as 'contextual constructionism'. They argue that such researchers assume that 'we will understand the empirical world better if we pay attention to the manner in which social problems emerge, and at a more basic level, they also assume that understanding the empirical world is desirable. That is, contextual constructionism is inspired by a sociological imagination' (p. 139). Brown (1995) further explains that contextual constructionists can give credence to actual conditions, such as medical illness, without putting primary emphasis on the condition. This research most comfortably adheres to these epistemological positionings. As such, the ensuing discussions are underpinned by these assumptions.

### **3.3 CHOOSING THE RESEARCH METHOD**

Burr (2003: 24) points out that although there are no research methods that are intrinsically social constructionist, the propensity for

researchers to value the social meanings of accounts and discourses often logically leads to qualitative techniques as the research method of choice. In practice this regularly transpires as an analysis of interview transcripts and written texts of other kinds. In keeping with these assertions, this project aims to '[view] events, action, norms, values, etc. from the perspective of the people who are being studied' (Bryman, 1992: 61). Consequently, interviews were considered to be the most appropriate method for this research. Three forms of interview were considered for this research project: unstructured interviews, focus groups and semi-structured interviews. These are critically discussed in turn below.

Unstructured interviews are particularly popular in heavily qualitative fields of research. Bryman (2001: 314) comments: '[t]here may be just a single question that the interviewer asks the interviewee and then is allowed to follow freely, with the interviewer simply responding to points that seem worthy of being followed up'. The unstructured interview allows the respondent talk at length about a topic without the intervention of the interviewer. As my research intended to elicit meanings and experiences that shape carers lives, unstructured interviews were initially considered to be a possibly suitable method. In this way, an interview would be shaped by what the carer deemed important for discussion, without being influenced by my research agenda. This is advantageous as an interviewer may unintentionally interrupt the respondent's flow of speech and inadvertently lose

valuable information. Due to the unstructured nature of the method, however, the interviews can be very time-consuming, often lasting many hours (Ding and Minh Ho Dac, 2005). Consequently, the transcription and analysis process is lengthy, often producing much irrelevant data. Furthermore, this research aims to answer three research questions. As such, some structure was deemed to be of particular importance so that these questions could be answered within the time each respondent was interviewed. These factors are particularly salient when considering the strict time frame imposed on this project and as such unstructured interviews were rejected on the grounds of their lack of practicality for use within this study.

Focus group methods allow the researcher to carry out group interviews of up to six participants (Greenbaum, 1998). This research method has been successful for some social researchers investigating illness and disability (e.g. Lester and Tritter, 2005). It allows individuals to share common experiences, which can be positive and liberating. Additionally, in some situations participants speak more freely producing rich data (Kitzinger, 1995). However, there are frequently particular participants that dominate the session and it often requires two researchers present to allow every voice in the group to be heard. Furthermore, Silverman (2007) argues that due to the number of respondents contributing to the discussion, the core focus of the meeting can be easily lost. In response, Fontana and Frey (1998) suggest that the method should also be carried out in conjunction with individual interviews. These

issues question the use of this method for this research as there will only be one researcher present during the fieldwork, and multiple methods are considered to be too time consuming.

Semi-structured interviews were eventually chosen as the interview method for this research. Britten (1995: 252) defines the method as 'conducted on the basis of a loose structure consisting of open ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail'. Consequently, an interview guide was designed prior to entering the field<sup>8</sup> so that each respondent could answer relevant questions pertaining to the research questions. Furthermore, the interviews could be guided by introducing a new question if a respondent digressed from the focus of the research topic. The flexibility of the method also enabled the participants to respond to issues or themes that I had not previously considered. Bryman (2001: 313) explains, semi-structured interviewing allows the interviewer to 'respond [...] to the direction in which interviewees take the interviews'. Consequently, this method allowed a number of themes to emerge from the interviews that were unpredictable at the research design stages.

Wengraf (2001) argues that within semi-structured interviewing, the researcher's purpose and theory is crucial. In this way, he warns those

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<sup>8</sup> See Appendix 07 for a copy of the interview guide for carers, and Appendix 08 for a copy of the interview guide for professional respondents. See section 3.6 for a discussion of how the interviews were carried out.

who undertake this method to be especially attentive to the design of the research questions. This constitutes one of the biggest challenges of semi-structured interviews. Bryman (2001) argues that although the method allows a researcher to specifically address the research aims within the study, they must be careful not to ask 'leading questions'. Britten (1995) argues that 'the novice research interviewer needs to notice how directive he or she is being, whether leading questions are being asked, whether cues are picked up or ignored, and whether interviewees are given enough time to explain what they mean'. In response to this I aimed to be reflexive about these challenges to the method and remain aware of them throughout the fieldwork.

### **3.4 SAMPLING AND ACCESS**

This section examines how access to respondents was negotiated within the study. It explores the difficulties in accessing Muslim family carers, which has been echoed by other researchers attempting to conduct research with hard-to-reach populations. The section examines how access to respondents required a flexible approach, whereby arrangements needed to be adapted and developed in response to the requirements of both gatekeepers and participants.

As such, further to a discussion about attempts to access respondents for interview, three subsections explore how gatekeepers to Muslim family carers expressed concerns about granting access. These include

concerns about the formality of the interview process, conducting research on a group with 'research fatigue' (Clark, 2008), and the seemingly problematic nature of the consent form. Further to these subsections, the discussion returns to discussing access issues and the importance of developing trust with gatekeepers. The section closes with a discussion of the challenges faced when attempting to locate contacts and gatekeepers for hard-to-reach groups.

A small research project conducted for my Masters degree in 2005 (see section 1.3 for a discussion of this experience) suggested that access to potential interviewees could be difficult. In response to these predictions, I ensured that I remained somewhat flexible to the needs and requirements of my target population, whilst keeping in mind my obligation to good research practice. My predictions were correct and my attempts to begin accessing potential respondents at the end of May 2006 were complex.

Internet searches were primarily employed to find organisations that potentially interact with Muslim carers. Fourteen organisations were initially identified and contacted by letter. All letters were constructed on 'University of Nottingham' headed paper, identified the key objectives of the research, detailed my interest in their organisation, and explained how I would subsequently telephone them for a further discussion<sup>9</sup>.

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<sup>9</sup> Please see Appendix 03 for the template used in this initial 'mail out'.

This attempt to access Muslim carers was unsuccessful; however, it often led to being given the details of other potential gatekeepers such as Muslim community groups, respected Muslim leaders and carer groups. I subsequently constructed a spreadsheet of potential gatekeepers, their name, the organisation, details of our previous conversations and the date of our next scheduled contact. Chart 3.1 presents a fictitious extract to demonstrate this system<sup>10</sup>.

**Table 3.1: Fictitious Extract from Contacts Spreadsheet**

Name	Organisation	Contact Detail	Details	Action
Aaliya Banks	East Carers - Chairperson	0123 45678	Telephoned 3/3/07 – left message.	Call 5/1/07
No contact name	Carers' Organisation	carers@carers.com	Telephoned 5/3/07	Asked if I could call back 9am 6/3/07
Brian Day	Welcome Carers – Outreach worker	0987 65432	Telephoned 5/3/07 – no answer	Call 6/7/07

This system led to obtaining the details of unofficial carer groups, respected Muslim figures within communities nationwide, social workers and support workers that could often only be accessed by 'word of

<sup>10</sup> The names and contact details included in Table 3.1 have been fictitiously created for demonstration purposes only.



mouth'. Atkinson and Flint (2001) refer to this form of sampling as 'chain referral'. They argue that when previous 'knowledge of insiders' is unavailable to a researcher, people in positions of relative authority and proximity can provide a route into the required population.

Once I was in contact with a potential gatekeeper, I would discuss with them my possible access to the Muslim family carers they supported. This was generally met with significant resistance. Gatekeepers would often describe how they were concerned that the research could undermine or jeopardise their professional relationship with the carers. After some significant time elapsed attempting to negotiate access, I noticed that there were a number of themes that seemed to be emerging from the accounts that these gatekeepers were sharing with me about their professional responsibilities, and their role within the community. Consequently, I chose to interview these individuals. This served several purposes. Firstly, it acted as a sampling strategy in that it reassured potential gatekeepers of how the interviews were conducted. Secondly, it allowed me to collect additional data that subsequently illuminated aspects of the experiences of Muslim family carers. As such, their voices are included in the final section of Chapter Six to explore the role of the carers' organisation in the support networks of Muslim family carers. Thirdly, it allowed me to explore in more detail how my conduct within the field could support good research practice. Details of these interviews are discussed in section 3.10.

Gatekeepers generally cited three main factors as to why my access to Muslim family carers was initially restricted. These included a fear that the research process could undermine the relationship between the carer and the gatekeeper, apathy towards academic research due to being previously studied by other researchers, and a concern for the welfare of the carer during the interview process. These anxieties shaped how the majority of the respondents in the study were subsequently accessed. These issues are addressed separately below.

#### **3.4.1 'DON'T BE TOO FORMAL, ACT LIKE YOU'VE KNOWN THEM FOR YEARS'**

Most gatekeepers that I spoke with agreed that Muslim family carers are a hard-to-reach group. A number of Asian carers' organisations that I contacted did not currently support any Muslims. These organisations were obviously unable to assist me in accessing respondents.

Individuals and organisations who were in some contact with Muslim carers often spoke at length about how their own access to Muslim carers had been difficult and complicated. Some described how respected members of the local Muslim community were often employed to encourage Muslim carers to seek support and assistance in their caring role. These gatekeepers presented very similar explanations of how access to Muslim carers required a specific approach that seemed to contradict traditional professional relationships (this is analysed in more detail in Chapter Six). The extract below is taken from an interview with Jaya, a manager of a BME carers'

organisation. She uses an example of a particular Muslim service user to describe how her bosses sometimes did not understand what is required to support Muslim carers.

She [Muslim carer] only has two hours to be out between changing her husband. We have these five minutes in the car and she has cried and cried. She won't see a counsellor, she won't see any other services, she won't allow herself the English class to come to. But [attending the carer group] means so much to them and then my bosses say, 'why do you need the transport?' and I think God how can you even say that? You can't say it. It's so important and if we couldn't provide the transport, the five minutes [there] and five minutes back, she wouldn't attend the classes. I mean she would not allow herself no time at all so it is just so important.

Providing transport for a carer who does not have 'statemented' medical reason for requiring it, may be deemed by some service providers as unnecessary, however, Jaya's account above documents how this service is essential for some carers. Her account echoes many of the Gatekeepers that I spoke with, who described how supporting Muslim family carers often required them to transcend traditional professional boundaries. Some spoke about how they were available for carers to telephone them, often late into the night, to talk through concerns. Others described how carers in the community would visit them at home to discuss issues. These gatekeepers would often mediate family disputes, provide lifts, and attend medical appointments, weddings and

parties. Consequently, gatekeepers regularly described that they were always 'on call'. For example, Gazala works for a Bangladeshi community organisation. A significant aspect of her professional role is supporting Bangladeshi Muslim carers. She described how she was sometimes unable to tell service users not to contact her at home, even if it interferes with her private life.

[P]eople do recognise me because of the work that I do. I mean I do get pestered at home, because I think when you are in such a close-knit community I think that people just think that when you finish work here that you work from home as well. Initially when I started off it wasn't too much of a bother but I've got a little one now and sometimes I think it isn't fair on my daughter that I'm on the phone. Sometimes you can't say no, you know, because it's rude to tell them 'actually I'm doing something else at the moment'.

Many gatekeepers were concerned that carrying out the interviews would be distressing for the carers in some way, and may jeopardise the relationship between the carer and the gatekeeper. During an interview with Aalia, an Asian carer group leader, she advised that when attempting to access Muslim carers: 'Don't be too formal; act like you've known them for years'. This seemed to capture the sentiments of most potential gatekeepers I accessed. Subsequently, access to Muslim carers seemed to be dependent upon me being as informal as possible whilst in the field.

I responded to this in a number of key areas. Firstly, all gatekeepers to carers' organisations urged me to get to know the carers that they supported before undertaking an interview. This meant attending a number of social events and meetings. Similarly, Katbamna *et al.* (1998) reported being asked by several organisations to speak to the users of the service and committee members running support groups, which resulted in the organisations being visited two or three times before data collection commenced. Secondly, I was advised that my attire was too formal (a loose fitting trouser suit). I was also asked to 'lose the workbag' (a shoulder bag that carried my information sheets, interview guide, recording equipment and food), by one carer group leader. I consequently wore loose fitting trousers, a long sleeved top and a backpack, which was received very positively by all gatekeepers I subsequently visited.

A final request was to not record the interviews. Many gatekeepers saw this as potentially distressing for a carer and render the interview process too formal. In my attempt to be flexible whilst continuing to uphold good research practices, I insisted that this was an integral research tool in which to present most accurately the experiences of the respondents. The only alternative to recording the interviews would have been to write extensive notes, however, I did not consider my note-taking skills to be strong enough to produce meaningful data. Furthermore, I considered my taking notes would distract from concentrating on the respondent and consequently affect the flow, and

therefore the quality of the interview. Once these factors were explained, all gatekeepers retracted the request, however, it led to some carers not wishing to be included in the research and I accepted this as a reasonable consequence of my decision.

In most cases I had spent some time with a respondent prior to the interview. This had mainly been at social events, which I believe assisted in making the carers feel more relaxed and able to speak more openly about their experiences. However, I also wanted to ensure that respondents did not misinterpret our relationship as being beyond that of interviewer/interviewee, which I would consider to be potentially exploitative in order to encourage the respondents to share more. Consequently, I made sure that the setting of each interview followed a routine. Respondents would be given an information sheet<sup>11</sup>, which I would read aloud and invite the respondent to voice any questions or concerns. The tape recorder would then be switched on and the interview would commence. Each interview would finish by inviting the respondent to offer any further comments not covered by the contents of the interview. The tape would then be switched off. These routines demarcated the interview from everyday conversations or naturally occurring talk between friends.

### **3.4.2 RESEARCHING THE OVER-RESEARCHED**

Some gatekeepers of potential organisations explained that their

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<sup>11</sup> Please refer to Appendix 06 for a copy of this information sheet.

reticence to grant me access to Muslim carers was due to the fact that they had been involved in a number of previous research projects. They explained that these studies had often caused significant disruption to the group, without any significant gain to the organisation. They also described a number of negative consequences of being involved with previous projects that made them cautious of potential researchers. Firstly, they argued that some interviews had caused carers to become distressed. Secondly, they described how researchers had made promises to the group that had not been fulfilled. Finally, gatekeepers described that their motivation to take part in a research project was based on a desire to improve the situation of the carers they supported, however, they rarely observed any significant changes.

Katbamna *et al.* (1998: 10) reported similar findings in their study of carers from South Asian communities. They argued that '[s]ome community workers were cynical about the research and commented that 'enough research' had been done on the Asian community with no feedback or positive gain to the community'. Similarly, Clark (2008: 953) argues that 'claims of over-researching are likely to be reported in contexts where repeated engagements do not lead to any experience of change or where the engagement comes into conflict with the primary aims and interests of the research group'.

In response to this situation I made it clear to all gatekeepers, both the research objectives, and how the findings would be disseminated<sup>12</sup>. I outlined very clearly that the research was relatively small-scale and would not have any direct or immediate impact on policy change. This presented a risk that potential gatekeepers would fail to see any benefit of being involved with the research. I attempted to tackle this issue in two ways. Firstly, I explained that my findings would be presented at academic conferences, and hopefully published in journals, which may illuminate the experiences of the Muslim family carers within some academic circles. Secondly, I offered to provide a short summary of some of the main findings of the study. Further to this, I offered to return to each carers' organisation to speak about my research and its findings. Alty and Rodham (1998) point out that they have both successfully accessed target research groups in this way by '(a) reassuring prospective organisations of the confidential nature of the research and (b) promising a report or summary of the research upon its completion, which will be provided on request (p. 276)'.

Three out of the four carers' organisations eventually accessed were happy with this negotiation. The fourth group had less involvement in the research and did not take up the offer of receiving a summary document. Obviously, a considerable amount of time has elapsed since the data collection. To reassure these organisations that I still intend to fulfil my commitments, I send occasional emails to summarise my

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<sup>12</sup> See section 3.8.3 for an ethical discussion of the dissemination of findings.



progress.

### **3.4.3 A DISCUSSION ABOUT CONSENT FORMS**

Consent forms are a useful method of reassuring respondents about their involvement in a research project. Signed by both the interviewer and interviewee, it often acts as an informal contract between the two parties, outlining how the information that the respondent provides will be protected by the good research practice of the interviewer. This method was considered to be an important aspect of the research design, and was used in the first three interviews carried out with carers<sup>13</sup>. It was presented to the respondent at the beginning of the meeting, whereby a copy was handed over and read aloud. This was to account for possible language barriers to written English, even though all three respondents were English speaking. The interviewee was then invited to ask questions and voice any concerns, before the interview commenced.

In all three cases the consent form seemed to be negatively received. The discomfort appeared to stem from the act of signing the form. Perhaps it was reminiscent of other more formal care assessments, financial arrangements such as benefits, and any other contract that ultimately impacted on the lives of the carers and their families. This may have been exacerbated by possible language barriers that could

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<sup>13</sup> See Appendix 04 for a copy of the consent form used in the first three interviews conducted with carers.

increase the respondents' sense of unease at having to sign the form. Daria cares for her elderly mother with breast cancer. She was the last to be interviewed with a consent form. At the end of the interview she was asked if she would like to add anything. She described how some carers might be concerned that their involvement in the study could result in their benefits being removed. In other words, respondents may potentially regard the interview as a covert benefits assessment.

There are some people who are caring but they claim from the social and they don't want to speak about it but eh we are not claiming anything so that might be one reason why you can't eh [access carers]... [t]hey might think that they might lose the benefit or anything like that.

Daria's additional comment that 'we are not claiming anything' made me question if she too was concerned about there being negative consequences of being involved in the research. This raised both ethical and methodological issues that needed addressing before re-entering the field. I could not hope to be conforming to good research practice if my respondents were concerned about the repercussions of being involved. Furthermore, this could have serious implications on the data collected. An interview should attempt to create an environment where the interviewee feels comfortable to speak openly about their experiences. If my respondents felt anxious about the interview, then this aim could not be fulfilled. The consent form was identified as a key area that could be adapted to reduce the formality of the interview. Its

usage was subsequently reviewed and replaced with a basic information sheet.

A paper copy of the information sheet was given to each respondent and read aloud before the interview commenced. This formalised the details already explained to the respondent, reassuring interviewees that they would remain anonymous within the thesis and any other form of dissemination in the future. It also contained my name and email address in case they had any subsequent concerns or were unclear about any aspect of the study and wished to contact me to discuss this (see section 3.6 for more information on the conduct of the interviews, and Appendix 06 for a copy of the information sheet). The information sheet was used for the remainder of the interviews undertaken and seemed to elicit a more favourable reaction from respondents.

Returning to sampling and access issues, Katbamna *et al.* (1998: 10) commented that when attempting to gain access to Asian carers for their research; '[g]aining the trust and support of key workers was paramount as they helped with the identification of carers and possible interviewees. It was therefore vital to behave in a professional manner and tactfully deal with difficult situations should they arise'. Their comments were also observed in my research and I believe that my commitment to being professional, polite, friendly, honest and flexible led to me being granted access by five gatekeepers. Four gatekeepers were carers' organisations, and descriptions of each group are provided

in the following section. The final gatekeeper was Bahir, a Muslim religious leader, who specialised in issues of health, illness and disability. She granted access to four carers for interview.

A number of challenges were encountered when attempting to identify organisations and individuals thought to be potentially in contact with Muslim family carers. These difficulties are detailed in bullet points below.

- The contact details of organisations were often incorrect or dated on websites. A significant amount of time was required to locate new addresses, telephone numbers and email addresses.
- I was often provided with inaccurate telephone numbers of individuals and organisations, which often led having to return to the people who had originally provided the information to try to obtain the correct number.
- It was quite common to find that organisations listed on websites or recommended by people I spoke with, were no longer operating. However, it often took some considerable time to discover that the organisation had not simply been relocated or that its name had changed.
- Meetings with potential gatekeepers were regularly cancelled at the last minute after a journey had been undertaken, which resulted in wasted time and travel.

- Potential gatekeepers sometimes did not arrive for our scheduled meeting, even though meetings were always confirmed prior to setting out on a journey, which resulted in wasted time and journeys.
- Very regularly telephone calls and emails were not returned or answered, which required me to 'chase' people up, often leaving numerous messages on answer-phones or with colleagues.
- A national carers' organisation was very interested in being involved with the research and to act as a gatekeeper to the Muslim family carers they supported. Negotiations with the organisation were rather time consuming and at a late stage they requested that I obtain ethical clearance from the National Research Ethics Service. Considering how lengthy this process can be, the time constraints placed on the research, and the stage I was currently at in my data collection, I did not agree to their request, and contact with the organisation was subsequently lost.

### **3.5 SUMMARY OF THE FOUR CARER SUPPORT ORGANISATIONS ACCESSED**

As the previous section described, four carers' organisations were eventually accessed, who acted as gatekeepers to accessing Muslim family carers for interview. Furthermore, some of the professionals who worked at these organisations were also interviewed, and their responses highlighted the important role of a specifically Muslim carers'

organisation (this is addressed in Chapter Six). This section describes how each organisation was structured, and how many carers from each were accessed for interview. The process of accessing professionals for interview will be discussed in more detail in section 3.10.

All four organisations were similar in that they aimed to support the specific needs of Muslim carers and were run predominantly by British Muslims who were actively involved with the Muslim community. These organisations also provided slightly different services and are described below.

### **3.5.1 ORGANISATION A**

Based in the south east of England, this was the first carers' organisation that was accessed and is the least formal of the four. It was founded and is run by Basir, who decided to set up the organisation after a car accident paralysed his wife and left him with a disability. The accident also killed his son and his mother-in-law. At the time of the research the organisation had been running for fourteen years. It's primary objective is to provide respite for disabled Muslims and their carers (Basir insists that the organisation's services are also open to non-Muslims, however, the majority of its service users are Muslim). Every Saturday the organisation meets in a community centre, where a cooked meal is served to carers and their disabled relatives. Basir spends much of the meeting feeding and socialising with the disabled members of the group so that the carers can relax and chat

with other carers. Basir also organises occasional day trips for its members, and at the time of the research he was planning a shopping trip.

Two carers were accessed and interviewed from this organisation.

### **3.5.2 ORGANISATION B**

Based in the West Midlands, this was the second organisation to be accessed for this research. It was founded and is run by Ghatsaan, a specialist social worker, who specifically works with carers from black and minority ethnic communities. It originally brought together a handful of Muslims for occasional coffee mornings, however, Ghatsaan developed the organisation and it now supports hundreds of Muslim carers in the area. As well as Ghatsaan, the organisation now also employs two other workers. Kaleemah is employed as a development worker, whose specific role is to build relationships with carers and families with a disabled relative and develop relations with government services such as the NHS. Zara is employed as a support worker and helps carers access services, benefits and support. The organisation has a permanent residence in a Muslim community building owned by Fawaz, a high profile Muslim community leader. The organisation encourages carers to attend 'training days' where certain health and social organisations give talks about disability, illness and available support. All events are interpreted into Urdu, include a cooked meal

and ten pounds towards travel expenses. Finally, the organisation provides day trips and shopping trips for carers and those they care for.

During the period of data collection, the organisation was expanding to develop a sister organisation that catered for the specific needs of Muslims with disabilities. This idea developed in response to the organisation realising that many mainstream support organisations, such as day care centres, were not considered by many of the Muslim carers that they supported to be suitable for those they cared for, due to religious and cultural differences.

Eight carers were accessed for interview from this organisation.

### **3.5.3 ORGANISATION C**

Based in the East Midlands, this was the third organisation to be accessed for this research. It's founders include Inaam, who was later employed as a Valuing People Officer in the East Midlands, and is now run by Abida, a prominent figure in the local Muslim community. The organisation focuses on providing respite, information, support and activities for Muslim carers and those they care for. It also provides specific volunteering opportunities for Muslims with learning disabilities at the organisation. Regular events such as a 'bring and buy' raise awareness of learning disability in the community, and pampering sessions whereby carers receive massages and *henna* painting, provide respite from those they care for. During the data collection the



organisation had put on a painting competition for the carers, whereby they were meeting regularly and painting a picture of their choice. The winner had painted a scene of herself on pilgrimage to Mecca. One important focus for the organisation was its sensitivity to religious and cultural issues, especially with regards to separating sexes. Finally, at the time that the data was being collected, a room at the premises of the organisation had been converted into a 'senses' room, with UV lights, fibre optics and fairy lights. This provided a stimulating and relaxing atmosphere for those who accessed the service.

Eleven carers were accessed for interview from this organisation.

#### **3.5.4 ORGANISATION D**

Based in the East Midlands, organisation D was the final organisation to be accessed for this research. The specific organisation was actually a subgroup within a subgroup of a much larger carers' organisation. The small organisation formed part of the organisation dedicated to carers from BME communities. The BME section of the organisation was run by Jaya, who had employed a woman active in the Muslim community to form a small carers group specifically for Muslim carers.

Unfortunately, Jaya was the only employee of this organisation who was interviewed. The organisation focuses on providing advice, support and information for carers. However, the support group for Muslim carers also provided social activities for both the carer and their cared for relatives, whereby they would be driven to and from their homes to

the premises. The carers would then eat, drink and socialise with other carers and the carer group leader. The group leader would also support the carers in making and attending doctors and hospital appointments, and visiting them at home for social visits and support.

Three carers were accessed for interview from this organisation.

### **3.6 CARRYING OUT THE INTERVIEWS**

Twenty-eight interviews with Muslim family carers were carried out at intervals over a period of sixteen months between May 2006 and September 2007. A further fifteen interviews were also carried out during this period with professionals, whose specific occupational role pertained to supporting Muslim family carers. This is discussed in section 3.10. Prior to entering the field, an interview guide was constructed to shape the interviews and align the questions with the research questions. The guide consisted of a set of open-ended questions (see Rugg and Petre (2007) for a useful discussion of constructing open-ended questions) that were kept either on my lap or on the table in front of me. Mason (2002: 67) argues that just because a researcher is planning a loosely structured or semi-structured interview, which is designed to feel like a 'conversation with purpose', does not mean that the interview structure does not require detailed and rigorous

planning. With recognition of this need, I made a detailed interview guide.<sup>14</sup>

The semi-structured nature of the interviews allowed the key areas of the research to be covered with each respondent (Britten, 1995; Bryman, 2001). At times these subjects were covered by the general flow of the conversation, so questions on the interview guide did not need to be specifically asked in all instances. Other participants were less vocal and the presence of the interview guide was able to support and encourage the talk. As discussed in section 3.3, the flexible nature of semi-structured interviews also allowed for the respondents to deviate and discuss topics that may not have been covered in the interview guide (Britten, 1995). A key aspect of the design of the interview guide was being aware of the language I used. Primarily, I avoided using abstract concepts, that the respondents might misunderstand, which could produce misleading data (Mason, 2002). Additionally, I avoided using certain words that I considered could cause unease or may not be understood due to language barriers. For example, it was revealed to me during an interview with Kaleemah, a development worker from Organisation B, that there was no word for 'relax' in Urdu.

A large proportion of carers interviewed for this research were primarily Urdu speaking. I subsequently adapted the planned interview question

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<sup>14</sup> See Appendix 07 for a copy of the interview guide for carers and Appendix 08 for the interview guide for professionals.

‘what do you do to relax?’ to ‘what do you do for fun?’ Additionally, I avoided using words such as ‘interview’, and replaced them with ‘conversation’ or ‘chat’ to assist in creating a non-judgemental, informal and safe space to speak. Gillham (2000) also alerts the interviewer to be aware of her or his behaviour when interviewing. He argues that an awareness of one’s body language is key to a successful interview. These include, listening rather than talking, being confident that interviews are sometimes slow to start, and not appearing anxious to ‘get a response’ (p.35).

The first part of the interview was designed as an ‘ice breaker’. This involved a set of questions that were easy to engage with and intended to establish an informal and friendly dynamic. I would ask about the person/people the respondent cares for and their name/names. Referring to the cared for relative(s) by their name assisted the interview in two ways: Firstly, it enabled an easier and more informal flow of conversation. This was especially pertinent for respondents caring for more than one person, whereby they did not need to keep reminding me of who was who. For example, Iqraam cares for three adult sons with learning disabilities. At the beginning of the interview we established the names and some general information about each son. It transpired that he had very different caring experiences with each son. Consequently, knowing the names and basic information about his sons enabled me to clearly follow the flow of his conversation. Secondly, it assisted in constructing a supportive and informal environment for the

carer to speak about their experiences. The aim of the interviews was to elicit the meaningful beliefs, experiences and perceptions from my respondents. This potentially required participants to speak in some depth about their personal lives. Referring to the carer and their families by their names at the outset of the interview contributed to creating a relaxed atmosphere.

Each respondent was also asked to describe a typical day from the time they get up to the time they go to bed. This question often produced some very interesting data about the participants experiences and perceptions of caring. Much of the overall data collected stemmed from responses to this question that were subsequently followed up by further questions. Rugg and Petre (2007) suggest that maintaining eye contact and not interrupting respondents are also useful methods for putting an interviewee at ease, which I attempted to follow throughout the duration of the interviews.

The interview then moved on to questions about accessing health and social services. Although these questions related to the second research question, I was reticent to start the main body of the interview with potentially sensitive and personal questions about religious belief. Respondents were asked about health and social services accessed; how regularly they visited a doctor or other health practitioner and if their cared for relative attended a day centre or other types of formal social activities. This would naturally lead to conversations about if

these services were accessed, perceived and experienced.

Respondents were then asked about how they felt being Muslim affected these experiences.

The third section of the interview guide led quite naturally from the previous section about religious adherence and accessing services to more general questions about their religious beliefs. This began by asking participants the very open question: 'What does being Muslim mean to you?' This was a particularly interesting aspect of the interview. Although it does not refer to care, respondents would often provide long accounts of their religious beliefs about caring, illness and disability, which highlighted how important faith was for many of the carers in the study in shaping their perceptions of their caring role. Respondents were also asked to explain what they consider to be the Muslim teachings of care, illness and disability. Being non-Muslim was particularly advantageous for this section of the interview because the respondent was always the 'religious expert', which meant that I was able to elicit clear, concise and detailed accounts of the respondents' religious beliefs. Elam and Fenton (2003) address the advantages of being an outsider to the research group. They argue that respondents are often more likely to provide detailed accounts to 'outsiders', as it is often assumed that they have no prior knowledge of the subject.

The final section of the interview was designed to elicit data about the types of support networks available to the carer being interviewed. It

explored the role of the family in providing help and support for their caring role. Other possible support networks were also explored, such as the local Imam, Mosque, community group members and carers groups. Exploring the role of the carers' organisation was particularly pertinent for many of the carers in the study as the majority of carers interviewed were accessed through their affiliation to a carer group. The interview closed with inviting respondents to add or speak about any issues not already covered.

At the start of each interview I gave each participant an information sheet to keep, which I also read aloud. It confirmed the details already explained to the respondent and reassured them that they would remain anonymous within the thesis and any other form of dissemination in the future. The information sheet also documented my name, telephone number and email address so that I could be contacted if a carer subsequently wished to discuss their inclusion in the research, or were worried about a their contribution (for a further discussion about the information sheet see 3.4.3, also see Appendix 06 for a copy of the information sheet). Interviews were recorded on small minidisk player with attached microphone. Stockdale (2002) provides an informative discussion on the types of recording equipment suitable for recording qualitative interviews, and advocates the use of a minidisk player for its transportability and high sound quality. Interviews lasted between 40 minutes and three hours. The interviews that lasted the longest were

usually due to the respondent providing in-depth accounts that they seemed to enjoy sharing.

Interviews either took place in the respondent's home (sixteen interviews) or in the office space of a carers' organisation (twelve interviews). Both situations had their own sets of challenges that will be addressed below. It was often not possible to interview a carer alone if they were interviewed at home. Many carers needed to attend to caring duties whilst responding to my questions. For example, Dunia cares for her son with severe learning and physical disabilities. Her husband works during the day leaving her to care for her son who needs consistent attention. The interview took place in her home while she went about her daily routines. The tape regularly had to be turned off and on so that she could carry out various caring duties. Katbamna *et al.* (1998) described similar experiences when interviewing Asian carers in their homes. They argued that their respondents were still able to speak openly, even if family members were present. This was also observed in my research. Even though I at times found it distracting attempting to speak over the wails of a disabled child, the participants in the study remained focused and seemingly unperturbed throughout.

Interviews carried out in the offices of a carers' organisation presented two main challenges. Firstly, interview times were much more restricted as carers often needed to return home to their caring duties. This meant that responses were sometimes less detailed than the interviews



carried out in a carer's own home. Secondly, of the twelve interviews carried out in an office space, ten were carried out with the use of an interpreter. Some researchers question the viability of using interpreters for collecting data. Temple (1997: 614) argues that the use of translators and interpreters: 'is not merely a technical matter that has little bearing on the outcome. It is of epistemological consequence as it influences what is "found"' (cited in Birbili, 2000). Careful consideration was given to my decision to include non-English speaking carers in the research, especially considering the possible threat to the reliability of the data collected. My final decision was based on my aim to understand how services were accessed and experienced by the respondents in the study. Much existing literature suggests that language barriers are a considerable contributor to the experiences of non-English speaking carers especially when attempting to access services and support (e.g. Ahmed and Rees Jones, 2008; Hasnain, 2008; Katbamna *et al.*, 2004; Manthorpe *et al.*, 2009; Owens and Randhawa, 2004; Worth *et al.*, 2009). I concluded that the responses of both English and non-English speaking carers would provide a fuller understanding of the caring experiences of Muslim family carers considering the financial and time restrictions imposed on the research.

### **3.7 DATA ANALYSIS**

After each interview I assigned the respondent with a pseudonym. I also wrote some basic notes about each interview in a research diary to help

me to remember the key aspects of each interview conducted.

Silverman (2007) strongly advocates keeping a research diary, which I have found to be a very useful habit while undertaking the study. Each interview was transcribed using Microsoft Word, with all identifying factors of each participant removed or replaced with a pseudonym.

The data analysis process began by thoroughly reading through each interview transcript and observing the most obvious themes within the data. These themes strongly correlated with the research questions. However, space was also given to the anomalous themes that emerged within the data, some of which proved to be particularly interesting. The 'highlight' function available in Microsoft Word was used to differentiate between themes. All the interviews were then systematically highlighted with four different colours pertaining to the three broad themes. Also any outstanding or unexpected themes initially identified within the data. These passages were then copied on to one of four Microsoft Word documents. These documents contained the responses of every interviewee relating to one of the three broad themes, and any outstanding themes.

Once the broad themes were identified, the data was further analysed by categorising each of the four documents into sub-themes. For example, respondents spoke in detail about their experiences and perceptions of accessing services. This constituted one of the three broad themes within the research. Within this theme, however, were a

number of sub-themes, which included gender, religious requirements, language barriers and a lack of knowledge about available resources. Each document was then organised under the sub-headings of each sub-theme.

Further themes were also identified within some of the sub-themes. For example, under 'Religious Requirements', respondents spoke about a number of issues including prayer facilities, *Halal* food, concerns about mixing sexes, consumption of alcohol and facilities for ritual cleansing.

This method of analysing the data was repeatedly undertaken to ensure that all themes were identified. The process was finally discontinued when the above procedure failed to produce any new themes. Lastly, each themed document was re-examined to identify patterns and links between the themes and the sampling variables: gender of the carer, affiliation to a carers' organisation, gender of the cared for relative(s), number of people cared for, and the relationship of the carer to the cared for relative(s). This was a particularly important process for understanding some of the incongruous or contradictory themes within the data. For example, this analysis revealed how carers were more likely to prevent their female cared for relatives from accessing social services such as day care centres, than respondents caring for men.

### **3.8 ETHICAL CONSIDERATIONS**

A commitment to good research practice also includes giving sufficient attention to the ethical issues surrounding the research. This is particularly important when studying potentially vulnerable groups of people, such as those accessed for interview in this research. This section draws on some of the key ethical issues present within this research. The British Sociological Association Statement of Ethical Practice (2002) provides a valuable reference here. As such, this section explores four key areas to which attention to ethical issues was of importance. These include informed consent, confidentiality, dissemination of findings, and securing the data. These are explored separately below.

#### **3.8.1. INFORMED CONSENT**

Sin (2005: 279) argues that '[r]esearch should, as far as possible, be based on freely given informed consent of research subjects who have been provided with adequate information on what is being done to them, the limits to their participation, as well as any potential risks they may incur by taking part in research'. Funk and Stajduhar (2009) argue that the potential risk of interviewing is particularly concerning for family caregivers as it may disrupt coping processes, expose a sense of failure and threaten their sense of identity. They go on to conclude, however, that interviewing can positively impact on coping for family caregivers if it is undertaken ethically and with sensitivity. In this way,

obtaining the informed consent from my sample was of particular importance.

Prior to the interview taking place, the majority of participants had been informed about the nature of the research and their involvement. This was done in one of four ways. Respondents accessed from Organisation B and C had been present at a coffee morning attended by myself where I gave a talk about the research, which was also translated into Urdu. Potential participants were then asked to volunteer if they wished to take part. Subjects from Organisation A were met and interviewed on the same day, however, I spent some considerable time explaining the research with the carers prior to respondents volunteering themselves to be part of the research. The carer group leader from Organisation D was met in advance and given an information sheet (see Appendix 05 for the information sheet given at this meeting), which was read out at a carers coffee morning. Potential respondents registered their interest with the carer group leader and a meeting was then set up in the offices of the organisation for the interviews to take place. The remaining four participants were accessed through Bahir, a Muslim religious leader. After our initial meeting, she contacted a number of carers in her community and informed them about the nature of my research before giving me the names and telephone numbers of those choosing to be involved.

I began each interview by (re)introducing myself and ensuring that I spent some time explaining the context, purpose, and future use of the research. Additionally, I ensured that all participants understood that they were free to discontinue the interview at any point, and that they were under no obligation to answer any of the questions asked. They were then given an information sheet to keep, which was also read aloud and, if an interpreter was present, translated into Urdu. Respondents were also invited to ask questions or voice concerns at any point during the interview.

### **3.8.2 CONFIDENTIALITY**

The British Sociological Association Statement of Ethical Practice (2002: 5) instructs us that '[t]he anonymity and privacy of those who participate in the research process should be respected. Personal information concerning research participants should be kept confidential'. To uphold this commitment, key identifying features were removed from the interview transcripts. These features included the names of participants, their families, Mosques, schools and any other organisations accessed. Street names and specific geographic locations were also removed. Where possible, all names were replaced with pseudonyms, otherwise, identifying features within the interview transcripts were replaced with the symbol: '\*\*\*\*'.

### **3.8.3 DISSEMINATION OF FINDINGS**

The British Sociological Association Statement of Ethical Practice (2002: 2) advises that researchers should be 'aware that they have some responsibility for the use to which their data may be put and for how the research is to be disseminated'. As part of the information sheet, participants were informed that the findings of the study would be predominantly circulated within academic circles. This was usually disappointing for participants who hoped that its impact could be far reaching. One participant even reflected at the end of their interview that the final thesis should 'be taken to number ten and given to the Prime Minister'. Although this research may be relatively small in scale, I remain aware of the continued media spotlight on Muslim affairs and the possible interest my research may be to certain journalists.

### **3.8.4 SECURING THE DATA**

The Statement of Ethical Practice for the British Sociological Association (2002) advises that '[a]ppropriate measures should be taken to store research data in a secure manner'. Consequently, interview transcripts and details about participants and gatekeepers were kept as password-protected files. Additionally, minidisk recordings of the interviews continue to be kept in a locked cabinet along with hard copies of the interview transcripts. The recordings will be kept for the appropriate amount of time before being destroyed in a secure manner.

### **3.9 REFLECTIONS ON THE RESEARCH PROCESS**

When analysing existing literature on being a reflexive researcher, it is apparent that locating oneself within one's own text can be controversial (Behar, 1996). Although it is described by some as 'mere navel gazing' (Letherby, 2000: 96), it is increasingly adopted within sociological research. However, some argue that it is still regarded as a 'risk' to the credibility of the study and the academic status of the researcher (Lee-Treweek and Linkogle, 2000).

Although many qualitative sociological researchers strive to be as objective as possible within their research, there is also a general view that the self as researcher has an impact on the research field (Hammersley and Atkinson, 1995). However, some scholars continue to be wary of presenting oneself within their writing, opting to remain anonymous. Letherby (2000) argues that students in the social sciences have been and sometimes still are urged not to write in the first person. In the past I have advised my students to do the same. Despite this, theorists have historically called for researchers to embrace the self within their work. C. Wright Mills (1959) notes: 'The social scientist is not some autonomous being standing outside society. No-one is outside society, the question is where he (sic) stands within it' (p.204). Similarly, Bourdieu (1996) questions: 'How can we claim to engage in the scientific investigation of presuppositions if we do not work to gain knowledge [science] of our own presuppositions?' (p.608)



In their book *Islam and Social Work*, Ashencaen Crabtree *et al.* (2008) argue that it is vital to be reflexive, especially when working in 'unfamiliar cultural terrain' (p.11), such as working with Muslims as a non-Muslim. They define reflexivity as 'the identification of speaker location' (p.11), and assert that it is useful in determining how the perspectives of the author impacts on the research process and outcome. Each contributor presents an account of her own speaker location, which, they argue, makes more explicit to the reader how their experiences and assumptions may have coloured their perspectives on issues. Moreover, how such locations have informed their views of social work and social welfare with Muslims.

This section is divided into three sub-sections. It first reviews ethnographic methodology and its relevance to the reflexive aspects of this study. A brief exploration of my own social location within the context of this research is subsequently presented. This precedes a subsection that reflects on the emotional aspects of conducting research, doing cross-cultural research and being a woman in the research field.

### **3.9.1 REFLEXIVITY AND ETHNOGRAPHIC METHODOLOGY**

Reflexivity has been widely endorsed by researchers adopting ethnographic methodology to underpin their work. Here, the notion of being reflexive often factors as a significant aspect in planning a research project, within the methods of data gathering, during data

analysis, and in writing up (see Etherington, 2004; Hammersley and Atkinson, 2007). Like all methodologies, most scholars agree that there is a complexity associated with attempting to define ethnography. This is discussed below.

Hammersley and Atkinson (2007: 3) define what ethnographers do in terms of methods of data collection. Here, the researcher participates 'overtly or covertly in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry'. These perspectives are echoed by Fife (2005), who argues that ethnographers attempt to understand how human beings 'make sense' within the context of their everyday lives. As such, researchers have traditionally made extensive use of participant-observation. O'Reilly (2005) draws on the definitional work of some of the main exponents of ethnography to construct what she terms as a 'minimal definition':

[E]thnography at least (in its minimal definition) is iterative-inductive research (that evolves in design through the study), drawing on a family of methods, involving direct and sustained contact with human agents, within the context of their daily lives (and cultures), watching what happens, listening to what is said, asking questions, and producing a richly written account that respects the irreducibility of human experience, that acknowledges the role of theory, as well as the

researcher's own role, and that views humans as part object/part subject (p.3).

O'Reilly's (2005) holistic definition acknowledges how immersing the self as the researcher into the lives of the researched, and recognising the effect that the self has on both how the data is gathered and ultimately the outcomes of the research, reflects much about the way in which I conducted my research. However, my study was not strictly ethnographic as it solely relies on the responses given in the semi-structured interviews that were conducted, however it borrows aspects of ethnographic methodology to inform a more sensitive and reflexive approach to how the data was gathered. For example, due to the sensitivity of my topic, I spent considerable time in the field whilst not doing interviews. As I discuss in section 3.4, I endeavoured to use this time to reflect on the most appropriate and sensitive methods of conducting the research. This was attempted by recording my observations whilst in the field in a research journal that I regularly reflected upon. Etherington (2004) argues that keeping a research journal is a helpful way of capturing 'our changing and developing understanding of method and content' (p.127). Moreover, she urges researchers to invest in the writing of a journal as a way of being reflexive within the research process.

The reflexive inclination of modern ethnographers is saliently captured within Davies' (2002) work on *Reflexive Ethnography*. She argues that the researcher has a profound effect on the people and circumstances

that they choose to study. Moreover, that all researchers are part of the object of their research and as a consequence, the conscientious researcher should be 'self-conscious' about their approach to their work. Defining reflexivity as 'turning back on oneself' (p.4), she argues that a process of 'self-reference' is relevant to all researchers. However, she also warns that a balance is required so that self-examination does not become self-absorption. In light of these debates, I present a somewhat brief account of my speaker location, which informs my interests in the discipline of sociology and of working with Muslims.

### **3.9.2 THE RESEARCHER'S STORY**

I am a British female, born to professional parents in the West Midlands. Growing up, my father worked as a salesperson for a transnational company. Consequently, his occupation required him to frequently travel, and we regularly had people from many different countries staying at our house for business purposes. Some of my first memories are of the rich cultural practices I observed of our guests, which I found fascinating from a young age.

At eleven I started secondary school. The school was located within a highly Muslim populated area, and as such, a significant minority of the school were Muslim. I was surprised to discover both the social divide between Muslims and non-Muslims in the school, and the frequency with which these divides were upheld by shocking racist stereotypes. When I was about fourteen our Religious Education class focused on

Islam. A student within the class was asked to demonstrate the performance of one of his daily prayers (*Namaaz*). The beauty of the Arabic words he chanted, and the physicality of the prayer was emotionally moving to the whole class and as he finished a stunned silence was followed by rapturous applause.

I can honestly say that at this moment I consciously solidified my interest in religion, which translated into my decision to take Sociology as one of my A-Levels. This interest subsequently grew throughout my academic journey, from my degree in Sociology to my Masters degree in Research Methods (Sociology). And so, as I describe in the introduction, when undertaking my Masters degree in 2005, and faced with the opportunity to submit a research proposal for a PhD project I gravitated towards the study of British Muslims.

### **3.9.3 REFLECTIONS ON INSIDER/OUTSIDER RESEARCH: EMOTION, CROSS-CULTURAL RESEARCH AND GENDER**

As this chapter has demonstrated, access to Muslim family carers in this research was challenging at times. Muslim carers may be seen to be a hard-to-reach group. Atkinson and Flint (2001) acknowledge how access to potentially marginalised and excluded groups can be difficult, especially if 'knowledge of insiders' are not previously known to the researcher. Similarly to Ashencaen Crabtree *et al.*'s (2008) experiences, as a non-Muslim, and having limited knowledge about Muslim cultural practices, I too was occasionally hampered by

regrettable social gaffes. Higginbottom and Serrant-Green (2005) note that whilst information about a research group can be gained from books, it is a 'guide rather than a true record of lived experience' (p.676). I think a consequence of this revelation was that at times I found undertaking the fieldwork quite emotionally demanding. This was not because I disliked the people I was researching, on the contrary I found myself in awe of the incredible strength of character and dedication that my respondents showed towards their caring role. I think it was because I felt guilty about how little I could offer them in relation to what they were offering me.

Higginbottom and Serrant-Green (2005) argue that academic research is often carried out to pursue career goals. Consequently, the 'results may have very little effect on the self identified needs of the target study populations' (p.667). These issues are discussed in section 3.4.2. This left me feeling guilty as I was aware that the more respondents I spoke to and the more they revealed about their experiences and needs, the more they were helping me to achieve my research aims.

Most of the carers I spoke to rarely had time for themselves and tried to wedge speaking to me between caring, cooking meals, going to the doctors, going to the Mosque and caring for other children. Similarly, many of the professionals I interviewed had dedicated their lives to their occupations. For example, Basir, the head of Organisation A, told me that he set up the organisation after his wife was severely disabled in a

car accident. He would drive up to ten people with disabilities and their carers from their home to a hired out space where he cooked them dinner and drove them home again. He told me that sometimes he would have to return the following day to clean up. He reiterated a number of times during the interview that no one can understand what it is like to care for a loved one unless they have direct experience of doing so. As we spoke about his financial difficulties to keep his organisation running, a girl who had been abandoned by her family because of her disabilities cried. She was used to being fed by Basir but because of our interview another volunteer was feeding her. I felt guilty both about taking his time when others seemed to have a greater need for his attention, and for the scholarship I was in receipt of, which could have significantly helped his organisation. As I discuss in section 3.4.2, I subsequently offered to write a summary of the research for each organisation I accessed and present the main findings at a carers meeting. However, at times this felt like a small offering.

Higginbottom and Serrant-Green (2005) argue that it is being in the field that teaches the researcher the most about fieldwork. Retrospectively, I am aware that some of the decisions I made about the fieldwork process were dependent upon a number of emotional encounters. My conduct during the research process became of particular interest to me when I realised that there were some aspects of my identity that I chose to divulge and some that I chose to withhold. This 'research identity' was unique because it was created gradually as I learned what was

‘acceptable’ and ‘unacceptable’ behaviour in the research group to which I was previously unfamiliar with. This idea adheres to Goffman’s theory of ‘role segregation’ and ‘audience segregation’ (1956), whereby individuals choose to display particular characteristics depending on the circumstances and audience. The quote below describes how embarrassment occurs when audience segregation breaks down:

Often important everyday occasions of embarrassment arise when the self projected is somehow confronted with another self which, though valid in other contexts, cannot be here sustained in harmony with the first. Embarrassment, then, leads us to the matter of “role segregation.” Each individual has more than one role [...] In every social system, however, there are times and places where audience segregation regularly breaks down and where individuals confront one another with selves incompatible with the ones they extend to each other on other occasions (Goffman, 1956: 269).

My ‘self projected’ seemed confronted with ‘another self’ during a tea break with a support worker. She asked me if I was married and I replied honestly that I was not married but lived with my partner. She was shocked by this and said ‘I thought you were traditional’.

Subsequently, she began to ask me questions about the nature of an unmarried relationship. She also made reference to a character in the soap ‘Eastenders’ who is defined by her sexual promiscuousness. I found myself justifying an aspect of my identity that I am generally private about. I was also embarrassed and concerned about any



professional repercussions that I may experience as a result of revealing an aspect of my personal identity that she explained to be unacceptable and inconceivable in her culture.

The above experiences led me to question conducting research with Muslims as a non-Muslim. I was very aware that my appearance and cultural practices were often different from those I sought to interview and that this could have a significant effect on the outcomes of my research. Higginbottom and Serrant-Green (2005) note that little research is available on the ethnicity of the researcher and the influence and effect it has on the research group.

My research experiences revealed a number of issues and sensitivities that are present when cross-culturally accessing sensitive groups including language barriers and knowledge of the culture. For example, Kaleemah, a Muslim development worker from Organisation B described how she was chosen for her role because she understood the cultural beliefs surrounding disability that are specific to a particular region of Pakistan. For example, she talked about how some carers are concerned that their disabled relatives are possessed by an evil spirit. She argued that she could sensitively inform carers of alternative perspectives because of her knowledge of the religion and culture. In this way, it may be argued that her 'insider' status within this particular group of Muslim carers allowed her to be more sensitive and knowledgeable of their particular needs. However, as a white, non-

Muslim researcher, I was an 'outsider' to my research group. The issue of insider/outsider research is explored in more detail below.

Corbin Dwyer and Buckle (2009) argue that reflecting on one's position as either an insider or an outsider is an essential aspect of conducting qualitative research. They assert that there are costs and benefits to both. They use reflections of their own research experiences to conclude that being an insider may provide a level of trust and openness from participants that may not be present otherwise.

Additionally, one has a starting point of commonality that affords access to groups that may be closed to outsiders. These assertions provide context to my own access issues, where I also experienced challenges when attempting to access a group with whom I previously had little experience or knowledge (see Atkinson and Flint (2001) for an in-depth discussion of accessing hard-to-reach or hidden populations. Also, see section 3.4 for a detailed discussion of access and sampling).

Conversely, Corbin Dwyer and Buckle (2009) also argue that as an insider, one 'might raise issues of undue influence of the researcher's perspective' (p. 59), projecting their own experiences and knowledge of a social group on to the research findings. Furthermore, some researchers have documented how their being a perceived insider by their research participants has led to assumptions being made about aspects of their identity (e.g. Yip, 2008). Nazir Chaudhry (1997) provides an interesting reflexive account of her researcher positionality

as a Pakistani Muslim researcher studying Muslims. She explores her difficulties in maintaining good relations with her research participants as she held fundamentally different beliefs about empowerment and feminism, which created tension. In light of these kinds of challenges, Corbin Dwyer and Buckle (2009) go on to suggest that one does not need to be an insider, or a member of a group being studied to adequately represent their experiences. Instead, they posit that:

[T]he core ingredient is not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience (p.59).

These arguments are echoed by Elam and Fenton (2003), who argue that although the presence of an ethnically matched interviewer is advantageous in some circumstances, it can also cause some respondents to assume that the interviewer knows what they are trying to say without giving a full explanation:

The presence of an ethnically matched interviewer can make it difficult for respondents to criticise cultural norms or can give rise to reluctance to admit to deviance from accepted behaviour or values [...] during a study of ethnicity and sexual health (Elam et al. 1999) a Muslim interviewer found that Muslim respondents tended to provide limited explanations during the interviews. Instead, respondents would reply with comments such as 'as you know', or 'as you have experienced too' or 'as we know from the Qur'ān' (p. 23)

In this way, it may be more useful to regard cross-cultural research, and the positioning of being an insider or outsider researcher, as being a highly complex and unpredictable issue, which is likely to produce particular accounts (Archer, 2002). Consequently, repeating the research using an ethnically matched, or Muslim interviewer would be a useful addition to knowledge. This is discussed in more detail in Chapter Seven.

Researchers are also increasingly acknowledging the importance of gender as a significant factor in the experience of researching others (Merchant and Ingram Willis, 2008; Merriam, 2009). Due to the nature of some research projects, some have argued that being a woman in the field limits the potential to explore certain male dominated social groups, especially in typically patriarchal societies (e.g. Altorki and Fawzi El-Solh, 1988). On the other hand, some researchers argue that being female is of paramount importance, especially when studying women. This has been a particular concern for feminist researchers, who have urged that research on women should be carried out by women. Citing Scottm (1989: 69-70), Kvale (1996: 73) describes feminist research as “qualitative research by women ‘on’ women” with a desire to make sense of women’s lives and experiences; it “must take women’s oppression as one of its basic assumptions”; it is research informed at every stage by an acknowledged political commitment’.

Although my research was not specifically focused on female family

carers, in keeping with existing knowledge (see section 2.3.1), the majority of my respondents were women, and I observed that my presence as a woman was of particular significance during the research process. Here, my gender seemed to act as a common identity whilst in the field that transcended ethnic or religious differences. For example, many of my respondents assumed that we shared common identities based on my being a woman. I was regularly referred to as a wife or mother, who understands what it means to care for others. Similarly, all respondents who wore a *niqab* that covered their face and head, would remove it when we were alone in an interview, or in a social setting away from men. I viewed this as a powerful symbolic act of my being accepted across the boundary from formal public life, into the private, domestic and social lives of the women I met. In this way my 'gender sameness' seemed to make me accepted as an 'insider'.

I came to interpret this affiliation that many of the carers, professionals and gatekeepers seemed to express as a form of 'sisterhood'. There has been significant scholarly investment in the concept of 'sisterhood', which has been instrumental in feminist discourses. Its classic definition is saliently captured by Thornton Dill (1983):

Sisterhood is generally understood as a nurturant, supportive feeling of attachment and loyalty to other women which grows out of a shared experience of oppression. A term reminiscent of familial relationships, it tends to focus upon the particular nurturant and reproductive roles of women and, more recently, upon commonalities of personal

experience (p. 132).

The definition of 'sisterhood' that Thornton Dill (1983) offers echoes my observations whilst in the field, where my gender seemed to have a positive uniting presence, which at times seemed to transcend class, ethnicity and race. These assertions are presented with some caution, whilst I also acknowledge the challenges that the concept of 'sisterhood' faces within feminist debates. Hooks (1986) concisely describes these challenges by arguing that:

Sisterhood evoked by women's liberationists was based on the idea of common oppression. Needless to say, it was primarily bourgeois white women, both liberal and radical in perspective, who professed belief in the notion of common oppression. The idea of 'common oppression' was a false and corrupt platform disguising and mystifying the true nature of women's varied and complex social reality. Women are divided by sexist attitudes, racism, class privilege, and a host of other prejudices (p.127).

Although I do not seek to challenge these important arguments; within the context of my research, I do assert that my female presence whilst in the field acted as a unifying identity between myself and the women I interacted with, which at times manifested in what seemed to be a form of 'sisterhood'.

### **3.9.4 SUMMARY**

This section presented a reflexive account of the research process. It first considered some of the key debates in the area. Ethnography was then explored in relation to how aspects of the methodology have influenced me in adopting a reflexive and sensitive approach to the study. A brief discussion of my speaker location attempted to provide context for how I came to conduct this research, and how my experiences may colour my own perspectives on certain issues. This preceded a discussion of how certain aspects of my identity (for example, my being a white, non-Muslim woman) may have impacted on my experiences within the field.

### **3.10 INTERVIEWING GATEKEEPERS**

This section discusses the additional interviews carried out with fifteen gatekeepers, or people whose occupation specifically involves working with, supporting, or working on behalf of Muslim family carers.

As discussed above, this research focuses on exploring the voices of twenty-eight carers interviewed for this project. Within the context of research questions one and two (see above), this decision seemed logical, especially as the topics largely revolve around an exploration of the carers self reflections and their perspectives of others. Moreover, the intention of the thesis itself is to hold at its centre a sociological exploration of the lives of the Muslim family carers interviewed.

However, a decision was made to include in the final data chapter the voices of a further fifteen interviews carried out with individuals whose professional occupation includes working with, supporting or working on behalf of Muslim family carers.

This decision was partly based on the aims of the third research question. The question intends to explore how the carers in the study both allowed and denied access to receiving support from both informal social networks such the family, and formal social networks such as carer groups. The chapter also explores how the four carers' organisations accessed (see section 3.5 for a summary of each organisation accessed) were able to provide the carers in the study with an opportunity to access formal support organisations. Understanding how this form of 'bridging social capital'<sup>15</sup> was made possible is illuminated by accounts given in these 'professional' interviews. These respondents often acted as gatekeepers to accessing formal support such as respite, benefits and home help.

As such, interviews with professionals provided an insight into how a link could be formed between the carers in the study, and state provided health and social services. Poston and Turnbull (2004) also combined the voices of both carers and professionals in their study of the role of religion for families of children with developmental disabilities, and these additional accounts illuminated their findings.

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<sup>15</sup> See section 2.4.1 for a definition of 'bridging' social capital and a wider discussion of the concept's application within this research.



Similarly, Mitchell (1996a; 1966b) successfully combined the voices of carers and professionals to explore the role of carer support groups.

The research techniques employed to interview professionals aligned very closely with those used to interview Muslim family carers. Semi-structured interviews were implemented as the best method to elicit detailed responses and guide the participants' accounts (see section 3.3 for a discussion of this research method). Prior to entering the field<sup>16</sup> an interview guide was designed for specific use with the professionals, however, its format remained similar to the interviews with carers (see Appendix 08 for a copy of the professionals interview guide). Each interview began with an explanation of its context, purpose and future use within the research. Respondents were given the same information sheet given to each carer interviewed, and asked to read it before the interview commenced (see Appendix 06 for a copy of the information sheet). Prior to the tape recorder being turned on, the participants were invited to ask questions and voice concerns. They were also advised that they could terminate the interview at any time and were not obliged to answer any of the questions.

The interview began by asking some 'ice-breaker' questions, which included 'tell me about a typical day doing your job', 'what are the best parts of your job?' and 'what are the worst parts of your job?' These

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<sup>16</sup> These respondents were accessed at the same time as the carers in the study. In fact, many of the professionals interviewed also acted as gatekeepers to the Muslim carers they supported. As such, section 3.4 also details the sampling and access strategies employed to invite professionals for interview.

questions were primarily designed as 'easy' questions that could assist in making the respondent feel relaxed in the interview setting. These 'ice-breakers' were followed by a set of questions designed to elicit responses about the nature of the interviewee's professional relationship to Muslim family carers. These included 'How important is the community in supporting Muslim family carers?' and 'Some researchers suggest that Muslim family carers 'care for their own'<sup>17</sup>. What is your perspective on this?' The interview closed with inviting respondents to add or speak about any issues not already covered.

Interviews lasted approximately one hour, with two interviews lasting between two and three hours. Respondents were given a choice about where they preferred the interview to take place. Two participants arranged for the interview to be carried out in a café near to their office, however, most chose to undertake the interview in an empty room at their place of work. Of the few interviews that did take place in the presence of others, the dynamic of the office seemed to be noisy with little sign of anyone paying attention to our meeting.

Each interview was transcribed and all identifying features of the individual removed and replaced with a pseudonym. This was particularly important for this sample, as some respondents were particularly well known within the community, with often unique occupational statuses. As such, the descriptions of these individuals

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<sup>17</sup> See Katbamna *et al.* (2004).

needed to be very vague for them to not be recognised in any future dissemination of the research. The data from this sample was analysed using the same techniques employed to analyse the data collected from the carers in the study (see section 3.7). The themes identified within this dataset were then examined against the themes identified in the data collected from Muslim carers. This process revealed the importance of a carers' organisation for supporting many of the carers in the study. For example, many carers spoke about how they did not access any services before joining a carers group. The interviews with professionals working at these organisations illuminated how they were able to work with both Muslim carers, and health and social services to allow carers to receive satisfactory formal support (see Chapter Six).

### **3.11 SUMMARY**

This chapter tells the story of how three research questions were operationalised and empirically applied to a chosen research method, which was subsequently used to carry out forty-three semi-structured interviews with twenty-eight carers and fifteen professionals. It details the barriers and complexities that I experienced whilst in the field, and how these difficulties were successfully negotiated and overcome. In this way, these experiences allowed me to develop 'key research skills' whilst in the field. It also discusses how the data was collected, transcribed and analysed into meaningful themes that form the basis of the ensuing three data chapters.

## **CHAPTER FOUR**

### **PERFORMING *ALLAH'S* WORK: PERCEIVING AND EXPERIENCING THE RELIGIOUS NATURE OF CARE**

#### **4.1 INTRODUCTION**

This chapter demarcates a shift in focus from the research design aspects of the study, to the data collected from twenty-eight interviews with Muslim family carers and a further fifteen professionals, whose occupation specifically relates to supporting Muslim family carers. It is the first of three data chapters that explore each of the three research questions originally proposed in Chapter One. In this way, this chapter explores the first research question, Chapter Five explores the second research question, and Chapter Six addresses the third research question. This chapter begins with mapping the biographical data of the respondents. Following this, the chapter explores how the respondents perceived their caring role to be informed by religious beliefs, and how this shaped the perceived performance of care.

Firstly, the importance of being Muslim for the carers in the study is explored. Here, the respondents present the complex entwining of their identities as carers and as Muslims. This discussion provides a basis for the ensuing section, whereby Weber's (1922) 'the problem of

theodicy' is applied to how the Muslim family carers in the study provided religious and spiritual explanations for both the affliction of illness or disability on the cared for relative, and their own role as a carer. This analysis reveals the complexity within the construction of religious beliefs for the carers in the study, which were based within popular Muslim theology, but adapted and reconstructed to comfort the respondents' individual circumstances.

Consequently, the conceptual tools provided by a relatively new body of literature introduced in Chapter Two, which pertains to the 'lived' and everyday experiences of religious life (Ammerman, 2007; McGuire, 2008) is used to frame how religious beliefs often intersected with the participants' day-to-day performances of caring routines. This section reveals the ways in which the respondents would take on obligations of religious rituals on behalf of a cared for relative as part of their caring role. Furthermore, spiritual significance was attached to their own performances of care, which often served as compensation for unmet religious obligations such as praying five times a day (*Namaaz*), or going on pilgrimage to Mecca (*Hajj*). This analysis reveals how the importance placed on being Muslim can significantly shape and influence the performance of care. These findings provide the basis for the following chapter (Chapter Five), whereby the significance of upholding certain religious and cultural expectations impacted upon how the participants' cared for relatives accessed and experienced health and social services.

## **4.2 BIOGRAPHICAL DATA OF THE RESPONDENTS**

This section presents the spread of respondents accessed for this research. Primarily, twenty-eight Muslim family carers were interviewed. A further fifteen 'professionals', whose occupation directly related to supporting Muslim family carers were also interviewed, and their accounts illuminate the carers' stories. Although occasional references are made to the professionals in the research, as their accounts provide further strength to some arguments presented, my primary focus is on exploring the perceptions, performances and negotiations of Muslim family carers. As such, prominence is not given to the professional voices within the research until the final section of Chapter Six, where they are used to explore how Muslim family carers access and experience formal support networks. Here, the unique and positive role of the specifically Muslim carers' organisation is examined. Consequently, the inclusion of the professional respondents allows for a more in-depth understanding of how the organisations were constructed to support the specific needs of their Muslim service users. As such, within this thesis, all references to 'respondents', 'participants' or 'interviewees' pertains to the carers in the study unless explicitly stated otherwise.

Six tables are presented below, which maps the most salient aspects of the respondents' biographical data. A seventh table is also added, which presents the spread of professionals in the study by gender and occupation.

**Table 4.1: Spread of Carers by Gender**

Gender of Respondent	Sample Number	Percentage
Female	25	89%
Male	3	11%

Table 4.1 shows the spread of respondents by gender. Current national statistics on care are based on the 2001 National Census. This provides a somewhat dated picture of care demographics in Britain; however, it remains an important and regularly cited resource for understanding the national spread of care. In keeping with the gender spread in this research, figures suggest that women provide the majority of informal care in the United Kingdom (3.4 million compared with 2.5 million men) (ONS, 2001). Further examinations of these figures also reveal that women are more likely to care if they are from Bangladeshi or Pakistani ethnic groups. Young *et al.* (2005: 28) argue that '[w]hile in most ethnic groups, females are 40 percent more likely to provide care, among Bangladeshi and Pakistanis women are twice as likely as men to be caregivers'. There are no current figures available on the gender spread of care by religion or faith. It is possible that due to some religious and cultural beliefs about care (discussed further in Chapter Six), Muslim women may be even more likely to provide care than men. However, further studies would need to be conducted to substantiate these predictions. In this way, it is unknown how representative my sample is,

however, it does represent care as the heavily feminine task that existing literature tends to suggest (see Finch and Mason, 1993; Dalley, 1996; Sullivan, 2000).

**Table 4.2: Affiliation to a Muslim Carers' Organisation**

<b>Organisation</b>	<b>Number</b>	<b>Percentage</b>
Organisation A	2	7%
Organisation B	8	29%
Organisation C	11	39%
Organisation D	3	11%
No Organisational Affiliation	4	14%

As discussed in Chapter Three, carers were predominantly accessed from four Muslim carers' organisations. Table 4.2 represents the number of carers accessed from each organisation. It also shows that four respondents were not accessed through their affiliation with a carers' organisation. These participants were accessed through Bahir, a Muslim religious leader also interviewed for this research.

There are no official statistics indicating how many carers access formal support organisations. It is expected that many more carers do not receive support from a carers' organisation than do (Chamba *et al.*, 1999, cited in Hepworth, 2005). The majority of carers accessed for this research were supported by a specifically Muslim carers' organisation.



This may constitute a limitation to this research, as the views and perspectives of Muslim family carers who are not supported by an organisation are limited to four respondents. One advantage that Table 4.2 highlights is the spread of carers accessed across four different organisations, which hopefully produced a more diverse spread of experiences (see section 3.5 for a description of each organisation accessed).

**Table 4.3: Relationship of the Carer to the Cared for Relative by Gender**

<b>Relationship to Cared for Person by Gender</b>	<b>Number</b>	<b>Percentage</b>
Female Caring for Children	18	64%
Female Caring for Spouse	1	4%
Female Caring for Parent	3	11%
Female Caring for Parent-in-law	1	4%
Female Caring for Spouse and Children	1	4%
Female Caring for Spouse and Parent-in-law	1	4%
Male Caring for Children	3	11%

Table 4.3 details the relationship of the cared for relative to the carer by gender. The majority of respondents interviewed were women caring for chronically ill or disabled children. However, it also reveals how a range of different respondents with different caring circumstances were also accessed. Furthermore, it shows that the women in the study were involved in more diverse caring situations than men, who only cared for disabled children. This may be a further reflection of the data collected in the 2001 National Census, which showed that Bangladeshi and Pakistani women are twice as likely to provide care as men (Young *et al.*, 2005).

**Table 4.4: Spread of Carers by the Number of Relatives Being Cared for**

<b>Number of People Cared for by Respondent</b>	<b>Number</b>	<b>Percentage</b>
One Person	22	79%
Two Persons	5	18%
Three Persons	1	4%

Table 4.4 reveals that the majority of carers interviewed cared for one relative. Although, there are no figures to suggest whether this table is representative of the sample population, it shows that a range of different carers were accessed, to produce a rich set of data.

**Table 4.5: Gender of Relative Being Cared For**

<b>Gender of Cared for Relative(s)</b>	<b>Sample Number</b>	<b>Percentage</b>
Female	11	39%
Male	14	50%
Female and Male	3	11%

Table 4.5 shows the spread of respondents by the gender of the cared for relative. There are currently no figures pertaining to the gender spread of British Muslims requiring care, however, the 2001 National Census reported that twenty-five percent of Muslim women and twenty-one percent of Muslim men reported living with a long-term illness or disability (ONS, 2001). These figures would render the sample within this research as slightly unrepresentative. However, this sample may also suggest that Muslim men may be more likely than Muslim women to receive care for their reported long-term illnesses and disabilities, which would be consistent with some of the findings highlighted in Chapter Six.

Table 4.6 shows the spread of respondents by ethnicity. Muslim communities in Britain tend to be predominantly from South Asian origin, particularly Pakistan (42.5%), Bangladesh (16.8%) and India (8.5%) (ONS, 2001). These statistics are consistent with the spread of

Muslim family carers in this research, as the majority were from South Asian origin. However, the additional presence of respondents who did not originate in South Asia may provide a wider range of accounts from carers with different ethnicities.

**Table 4.6: Spread of Carers by Ethnicity**

<b>Ethnic Origin of Carer</b>	<b>Sample Number</b>	<b>Percentage</b>
South Asian	24	86%
Moroccan	2	7%
Turkish	1	4%
South African	1	4%

Table 4.7 presents the spread of professional respondents interviewed for this research. Nine female and six male professionals were interviewed. This sample is somewhat gendered. This may be explained by evidence collected in Chapters Five and Six, whereby many of the carers in the study considered care to be a specifically female undertaking. Additionally, separating women from mixed male and female environments (*Purdah*) was also considered to be important to many respondents. Consequently, the slightly higher number of female professional respondents may be a response to the importance that some British Muslims continue place on issues around care remaining a fundamentally female task.

**Table 4.7: Spread of Professionals by Occupation and Gender**

<b>Occupation and Gender of 'Professional' Respondents</b>	<b>Number</b>	<b>Percentage</b>
Female Muslim Carer Group Leader	3	11%
Male Muslim Carer Group Leader	1	4%
Male Manager of Carer Group and Social Worker	1	4%
Female Support Worker at Muslim Carers' Organisation	2	7%
Female Asian Carer Group Leader	1	4%
Male Muslim Doctor	1	4%
Female Muslim Barrister	1	4%
Female Bangladeshi Liaison Worker	1	4%
Male Bangladeshi Disability Liaison worker	1	4%
Male Chairman of Local Muslim Organisation	1	4%
Female Muslim Religious Leader	1	4%
Male Muslim Community Group Leader and Council Worker	1	4%

This section presented the biographical details of the respondents accessed for interview in this research. The data provided in the tables above will be referred to throughout the remainder of the thesis to contextualise the research findings.

#### **4.3 PERFORMING *ALLAH'S* WORK: PERCEIVING AND EXPERIENCING THE RELIGIOUS NATURE OF CARE**

As discussed in Chapter Two, existing research on the religious beliefs of family carers has tended to focus on Christian denominations, exposing a significant gap in literature pertaining to the religious beliefs of Muslim family carers. In their study of the role of religion for families of children with disabilities, Poston and Turnbull (2004) argued that religious beliefs played a significant role in the lives of their respondents, who often attributed spiritual meaning to the disability of the child being cared for. Their research, among others (e.g. Atkin and Ahmed, 2000; Bennett *et al.* 1995; Dollahite, 2003; Skinner *et al.*, 2001), articulates the importance of religious belief for many individuals undertaking care for a family member.

The remainder of this chapter explores how the carers in the study interpreted their caring role to be informed and shaped by religious beliefs. The first section explores how the carers presented accounts suggesting that being Muslim formed a significant aspect of their identity. Furthermore, these identities seemed inextricably linked to their identities as carers. These findings support existing literature that

suggests that for many carers with religious identities, faith forms a significant and positive aspect of their lives. The following section examines in more depth how the carers in the study resolved their often challenging caring circumstances by constructing religious beliefs that both explained and supported their caring role. I came to understand these explanations as 'theodicies', therefore, Weber's (1922) classic work on 'the problem of theodicy' is employed as a theoretical framework with which to explore these beliefs. This analysis reveals the complexity within the construction of beliefs pertaining to their often difficult and demanding caring circumstances. The final section to this chapter explores how religious beliefs often intersected with the day-to-day routines of caregiving. The chapter concludes by revisiting the main points of each section and the wider implications of these findings.

As discussed in Chapter Three, interpreters were used for some of the interviews with Muslim family carers. However, if respondents understood the question, they would often directly respond. As such, some passages of interviews carried out with interpreters are presented in the third person, and some in the first person. When a quote is presented in the third person, a footnote is added to provide clarification.

#### **4.4 PERCEPTIONS OF BEING MUSLIM: EXPLORING THE LINK BETWEEN RELIGIOSITY AND CARE**

In order to explore the religious perceptions of the Muslim family carers in the study, I asked each carer to describe what being Muslim meant to them. This broad question aimed to decipher the extent to which the respondents considered their lives to be religiously informed by their Muslim identities. The majority of respondents explained that they considered themselves to be practising Muslims, and that being Muslim constituted a significant aspect of their everyday lives. Additionally, this initial question about a carer's religiosity also exposed a link between a respondent's religious beliefs and their role as a carer. Accounts of these beliefs are examined in this section.

When asked about their relationship to Islam, the majority of the carers in this study reported that they considered being Muslim to be a significant aspect of their identity. Both Vardah and Parvina demonstrated this importance by describing being Muslim as meaning 'everything' to them:

Vardah: Well *it means everything to me*. At this moment, I mean the whole of my life, I mean it is nothing without my religion (Vardah cares for two adult daughters with mild learning disabilities) (my emphasis).

Parvina: It means a lot. I love my religion, we eat *Halal*, we pray five times a day, we fast one month in the whole of the year. *It means*



*everything to me.* It teaches us to help the needy and the poor (Parvina cares for her son with Down's syndrome (my emphasis)).

Similarly, Iqraam, who cares for three adult sons with learning disabilities explained: 'If I am not a Muslim then I am nothing'. These findings are supported by existing literature, where some have suggested that the religiosity of British Muslims tends to be higher than other religious groups (Modood, 2003). Asking respondents about their religiosity also revealed the inextricable link between the carers' religious and spiritual beliefs, and their identity as carers. Parvina's allusion to helping the 'needy and the poor' (above) may indicate her awareness of her caring role when being asked about her relationship to being Muslim. More specifically, Dunia described how her relationship to God provided her with a sense of calm when her challenging caring situations left her feeling like she was 'losing her head':

Well, as a Muslim, I pray five times a day. Like meditation, my prayer brought me closer to my God, you know, having that faith and dealing with it. Most of the things I was feeling; it happened at a time when I was going through a lot of struggle in my life and with [son's name]. What I felt was everything with struggle came ease. I saw that I didn't get my ease straight away, it was only with a struggle, which I had, and this is what our faith actually tells us, and then ease came. When you put that in the back of your head, it helps you get on with your life, rather than leaving yourself in panic attack or thinking 'oh my God I am

losing my mind?' You know? My faith helped me to get on with my life  
(Dunia cares for her son with severe physical and learning disabilities).

The description that Dunia provides about her relationship to Islam was indicative of many of the carers in the study, who reported that their faith in Islam was a significant support for their roles as carers. Similar findings were also reported in Zunzunegui *et al.*'s (1999) quantitative study of family, religion and depressive symptoms in caregivers of disabled elderly people in Spain. They argued that religiosity played an important role in the mental health of Spanish caregivers. Omera reflected these kinds of findings in this research, explaining that Muslim teachings about care and love supported her in her caring role:

I feel very lucky as a Muslim. I am proud to be Muslim. Islam teaches a lot of care and love in our religion. I know that there is a lot of- there is a lot else out there but I think by this way it helps with the caring  
(Omera cared for her elderly father-in-law before he died).

The role of religion for family carers remains relatively under explored, especially in relation to Muslim carers. Treloar (2002) found religious belief to be an important source of support for the respondents in her study of disability, spiritual beliefs and the church. She explained that a faith in God facilitated an effective coping mechanism for the respondents in her study (p. 599). In conclusion, she argued that religious beliefs influenced the ways the respondents lived their lives. As such, 'the participants chose to live out their lives with thankfulness

and joy despite difficulties common to experience with disability' (p. 594). The findings in this research support Treloar's conclusions, whereby the carers in the study often reported feeling supported in their caring role by their religious beliefs as Muslims.

The following section employs Weber's (1922) theoretical arguments about theodicy to explore in more depth the link the carers in the study presented between their religious beliefs as Muslims, and their identities as carers. However, it is important to be aware of the methodological issues surrounding the presentation of religious beliefs in an interview setting. Bywaters *et al.* (2003) argue that giving an explanation to an interviewer is an act of self presentation, which combines information, feelings and decisions about disclosure. Furthermore, they describe how explanations can serve a particular function. In this case, accounts of religious beliefs may provide a coping mechanism to manage feelings about a respondents' caring role. Bywaters *et al.*'s (2003) perspectives adhere to the social constructionist epistemology employed within this research. Consequently, these issues are kept in mind when analysing the accounts presented by the respondents interviewed for this study.

#### **4.5 THEODICIES OF SUFFERING AND CARE: RELIGIOUS AND SPIRITUAL PERCEPTIONS OF CARE, ILLNESS AND DISABILITY**

This section examines in more depth the construction of the respondents' religious beliefs pertaining to their caring role, and the illness or disability of their cared for relative. Weber's (1922) work on 'the problem of theodicy' is employed here as a framework for categorising the religious beliefs that were presented by the carers to account for their often demanding and difficult circumstances. In his *Sociology of Religion*, Weber (1922) argued that in any monotheistic religion that conceptualises an omnipotent God, questions inevitably arise about how suffering and imperfection can exist if a kind and just God controls the world. As described in Chapter Two, Weber (1922) argued that different religions have solved these problems in various ways. He went on to argue that these solutions fall within three categories, or 'pure type' solutions to the problem of theodicy. These are employed here to explore how the respondents adopted and constructed beliefs that provided positive explanations for their caring role, and for the infliction of illness or disability on their cared for relative.

To provide a brief reminder of Weber's three pure type solutions to the problem of theodicy, Turner (1981) provides a concise description. Firstly, suffering in the world is compensated by a belief in a future kingdom where 'the poor and weak will replace the powerful as the true

followers of a righteous God' (p.148). Secondly, is the prolonged battle between good (God) and evil (the wickedness of man or demon).

Thirdly, (and in Weber's view, the most complete solution to the problem of theodicy) is the doctrine of *karma*. Here, rewards and suffering are awarded on the basis of moral and immoral actions and intentions. Individual fortune or misfortunes in this world are also the consequences of previous lives and reincarnations.

The data presented within this research suggested that the carers' responses aligned with Weber's first and third pure type solutions to the problem of theodicy in complex, incomplete and interrelated ways. The presence of Weber's second pure type was notably absent from the data, however, this may be consistent with the subsequent findings, whereby I argue that respondents tended to adopt and construct religious beliefs that comforted them in their caring role. As Weber's second pure type pertains to the dualism between good and evil, the notion that a carer's circumstance could involve negative interpretations may be incongruous to a healthy coping strategy.

In terms of Weber's first pure type solution to the problem of theodicy, most carers perceived their caring role to be a test from *Allah*, which, if undertaken with patience and steadfastness would be rewarded in the afterlife. In terms of Weber's third pure type solution to the problem of theodicy, some carers bestowed *karmic* principles to the performance of caring for a family member. These *karmic* beliefs were particularly

interesting in that only the positive aspects of the doctrine were presented. Here, accounts tended to exclude any beliefs that implicated the carer in their own circumstances of suffering. Consequently, these beliefs tended to reinforce ideas pertaining to how their caring role would be positively rewarded in the afterlife (which relates to Weber's first pure type). Moreover, respondents tended to adopt religious beliefs that supported their caring situations rather than beliefs that placed a negative spotlight or blame on their already challenging or demanding situations.

Consequently, the data collected suggested that the construction of complex theodicies by the carers in the study acted as a positive support for their often difficult and demanding circumstances. These findings adhere to existing literature that argues that religious belief is an important source of support for family carers (Atkin and Ahmed, 2000; Bennett *et al.*, 1995; Dollahite, 2003; Poston and Turnbull, 2004; Skinner *et al.*, 2001). This section will now explore how the carers in the study presented the first and third pure type solutions to the problem of theodicy. In the absence of respondents presenting negative beliefs or theodicies, this section will also discuss the implications of the respondents solely presenting positive religious interpretations of their caring role.

#### **4.5.1 THE FIRST PURE TYPE SOLUTION TO WEBER'S PROBLEM OF THEODICY: TESTS, REWARDS AND BLESSINGS**

The fundamental principle of Weber's first pure type solution to the problem of theodicy, is based on the belief that suffering in this world will be compensated by just rewards in the afterlife. Consequently, suffering is part of a divine plan that cannot be applied to human perspectives of justice. Popular Islamic theology strongly adheres to these principles. Rippin (2001) describes how a faith in Islam and a Muslim way of life is generally interpreted as being in complete submission to the will of *Allah*. Responses in this study aligned most strongly with this pure type.

Four main themes emerged that linked carers responses to Weber's first pure type solution to the problem of theodicy. Firstly, participants interpreted both their caring role and the illness or disability of their cared for relative to be part of a divine plan controlled by *Allah*. Secondly, the perception that *Allah* had omniscient control and divine intentions strongly linked with the perception that care, illness and disability is a test from *Allah*, to differentiate the steadfast follower from the weak, fickle adherent of Islam (Ahmed, 2000). Thirdly, performing care was generally perceived to be a spiritually valued task that would ultimately lead to being rewarded in heaven. Finally, parents of children with learning disabilities perceived these family members to be of particular spiritual significance, sent from *Allah* as a 'gift' to glean extra rewards in the afterlife. These themes are discussed separately below.

#### **4.5.1.1 Submitting to the Will of Allah**

Foziah cares for her mother who suffered a severe stroke ten years ago, which left her with significant physical disabilities and visual impairments. When asked about how she feels about her caring role she replied: 'Good, because it is what God has written for her and we accept that'. These types of responses were echoed by many of the respondents in the study, whereby a belief and trust in the omniscience of *Allah* provided comfort in their often difficult caring circumstances.

Tanweer and Daria articulated these beliefs in more detail:

Tanweer: I would probably say this better in my language, but I say that in whatever way God has left me, I am happy (Tanweer cares for her husband who is in the advanced stages of Multiple Sclerosis).

Daria: Whatever happens it happens from the God so you always have the faith in God that he'll do what is best for you because he has, you know, he has given you the life so you know he is there for you all the time. We have full faith in him (Daria cares for her elderly mother with breast cancer).

Accepting one's situation as the will of *Allah* has been acknowledged in much existing literature and some have argued that this encourages fatalism within Islamic communities. Miles (2002) argues that a submission to the will of *Allah* sometimes contradicts preventing or remedying disability. His research suggested that some Muslim parents rejected treatment for certain disabilities on the basis that the condition



was intended by *Allah* and should be accepted with fortitude. These perspectives have been strongly critiqued by many researchers who have argued that the Muslim respondents in their studies combined their belief in the will of *Allah* with an attempt to provide the best care for their loved ones. For example, Atkin and Ahmed's (2000) study of family caregiving and chronic illness, suggested that the majority of Muslim respondents in their research emphasised a belief in God, whereby *Allah* was seen to have given the condition and with it, the tools with which to cope. These beliefs, however, were often employed in conjunction with other coping strategies. Consequently, their religious beliefs did not 'encourage despondency or dependency. Families combined a trust in *Allah* with the need to provide 'the best care and treatment' (p. 62) for their chronically ill relatives. Similarly, the carers in this study did not present fatalistic beliefs about their caring role and most described it as a test from God that required undertaking to the best of one's ability. This is discussed in more detail below.

#### ***4.5.1.2 Care, Disability and Illness as a Test from Allah***

Iqraam cares for three adult sons with learning disabilities. He described how he interpreted the affliction of disability as a test from *Allah*. His response is typical of the types of accounts that the participants presented:

It's all God's will. It's God's will if you have a disability. It's a test from him to see how you're going to cope or how you are going to react to it.

Similarly, Meena and her husband care for their son with severe learning and physical disabilities. She explained how she perceives her son's disabilities to have been given by *Allah* to test her and her husband's patience. Consequently, she explains that she will attempt to provide the best possible care for her son.

[W]ith children like [son's name] they are a gift because they<sup>18</sup> have got several children and it is only [son's name] with the disability, therefore, it is not something that you bring on yourself, it is a test – it is a test from God for patience. They were saying that we have got everything God bless, you know, *Allah* has met our needs very well, [but] with [son's name] *Allah* would like to test – 'yes I have given you everything but how will you cope with this child, with this gift from me?' [...] They will do everything to please and care for this child [...] So it [the *Qur'an*] says do all that is possible for that child, do everything basically, what you can do, you know, go to the doctor, you know, talk about him. Also allow, or do all that is possible to make this person live independently as much as possible.

Vardah spoke more specifically about how her perception of her caring role as a test from *Allah* positively influences how she provides care for her two adult daughters with mild learning disabilities.

This is my test from God, so it has made me more tolerant and understanding, and it has made me want to cope I think, made me

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<sup>18</sup> Meena's interview was carried out with the use of an interpreter, which explains why some passages of the interview transcript are presented in the third person.

want to have more patience, and it is very easy to lose patience. You must know what your child is able to do and push them as far as they can, and do everything with kindness and slowly, I mean you can't shout at them. Some children have a routine; they like to do it a certain so, then you have to do it slowly, slowly.

Thus, the findings in this study challenge Miles's (2002) suggestions that interpreting *Allah* as being in complete control leads to a fatalistic attitude towards a family member with disabilities. On the contrary, the perception of care, illness and disability as a test from *Allah* seemed to provide the carers in the study with additional motivation for providing the best possible care for their relatives.

The interpretation of care as a test from *Allah* seemed to bestow the respondents in the study with a sense that their role was a spiritual undertaking. Some participants argued that their caring role was the consequence of being chosen by *Allah* as a worthy candidate for a challenging test, over and above other Muslims. As Dunia, who cares for her son with severe learning and physical disabilities argues: 'I have been chosen for this test because He knows I am strong enough to do it. God never gives you more than you can take'. These findings adhere to Bowker's (1970) perceptions of how the problem of suffering is resolved within Islam. He argues that the *Qur'an* is devoted to communicating that 'God is in control' (p.103) (see section 2.2.2 for a more detailed discussion of Bowker's work). By this assertion, all suffering is dictated and controlled by *Allah*. As such, it is purposeful.

Furthermore, 'the acceptance of suffering in an attitude of Islam (patient trust in the overriding control and mercy of God) is worthwhile because of the greater rewards to come' (Bowker, 1970: 116). The notion of receiving rewards for undertaking care was particularly significant within the data, and is explored below.

#### ***4.5.1.3 Religious Rewards for Caregiving, Illness and Disability***

Being rewarded for the undertaking of care was a salient theme within the data, and most respondents provided detailed descriptions of how these rewards would be received. This usually revolved around being sent to heaven without judgement, or receiving a better experience within heaven. These beliefs were sometimes reinforced by the perception that they were currently in receipt of rewards within their everyday lives on earth.

Fuseelah described how her difficult circumstances caring for her daughter with mild learning disabilities, is rewarded both on earth and the afterlife. She explained that her daughter refuses care from any other family member and that her needs are considered too mild by social services to provide any formal support. Fuseelah's situation is intensified by her reported need to work full-time. Although she considers her situation to be unsatisfactory and actively tries to get her daughter 're-statemented' so that she is eligible for respite services, she described how she has been bestowed with a sense of calm as a

reward for her undertaking of care. Furthermore, she will be rewarded in the afterlife:

When you die you go to paradise and when you are in the world you get peace, you are calm in yourself. Even now I am very tired and I don't get time for myself but I am not nervous or stressed, I am just calm about it and just happy the way my life is. It is just peace and contentment for me.

Similarly, Warda described that God considers caring for someone as comparable to undertaking a pilgrimage to Mecca (*Hajj*) seven times.

They say that it is very good to care for one person. They say that God will give you a reward like seven times you go Mecca, it is like seven times you have done this if you take care of one person like this. It is something like doing it seven times. God likes it so much (Warda cares for her son with learning and physical disabilities).

There were general inconsistencies in the perceptions of where beliefs about rewards originated. Although many cited the *Qur'an*, very few people quoted the same verses. Warda's comparison of going on pilgrimage to Mecca seven times was not repeated by any of the other respondents in the study. For example, Yalina explained that she interpreted the *Qur'anic* teachings of care as being rewarded by God with a trophy or award:

The *Qur'an's* teachings are that if you do good for looking after someone with a physical or learning disability, you know, like you get a trophy or an award for being good. It is like in Islam, they say that God rewards you in the end for doing something good for someone. Even if it is your child, even if it is the elderly, even if it is your mum or your dad, even if it is your cousin, even if it is your neighbour (Yalina cares for two children with severe learning and physical disabilities).

Although the carers in the study varied in how they perceived they would be rewarded for their caring, or where these beliefs originated, the consistency with which these beliefs were presented seemed to communicate a similar message: that care work was a worthwhile spiritual undertaking, which is valued by *Allah*.

As a consequence of these inconsistencies, accounts of the extent of the rewards that each carer perceived that they would receive, varied for each respondent. Closer examination of these accounts revealed that perceptions of the rewards received, generally depended upon the nature of the caring role undertaken. In this way, carers with more demanding caring situations were more likely to report greater rewards for their undertaking than carers with less demanding caring roles. For example, Dunia cares for her son with severe learning and physical disabilities. She is his sole carer as her husband works full-time and her family lives in a different part of the country. Furthermore, the severity of her son's disabilities means that he is unable to walk, talk or communicate. When asked about her religious beliefs, Dunia argued

that her caring role was her 'ticket to heaven', and that she would bypass any judgment for any sins committed.

In my faith it is believed that for looking after a child like this, or you are caring for anyone elderly or a child with special needs, in my religion it means it would be a straight ticket to heaven for me. So I don't need to worry about being questioned for any sins I might have done wrong, he has taken me to heaven because of his needs which I am caring for. How shall I say, because I am looking after him, I am getting blessed for that and he is my ticket to heaven.

Conversely, Bisma cares for her elderly mother-in-law. She shares her house with other adult relatives who she reports 'all muck in' to support her. When asked about her caring role, she argued that 'it is good. The *Qur'an* teaches us to go and see the ill people, and we will get a little reward for that'. These sentiments are not as bold as those made by Dunia, above, and may reflect the intensity of her caring role in comparison to some of the other carers in the study such as Bisma.

The discussions above present the ways in which adherence to Weber's first pure type solution to the problem of theodicy may be informed by the situational factors affecting the respondents. In this way, the extent to which the participants expressed that *Allah* was in control, and the degree to which the carers saw their caring role being rewarded in the afterlife may be informed by external variables that intersect each of the respondents' lives. In other words, the more the

suffering, the greater the reward. Bowker's (1970) arguments concur with these views. He argues:

[T]he Quran encourages men to accept suffering as a trial and as a chastisement for sins already committed. Several traditions developed this further by suggesting that it is often the best men that suffer most, because this shows how close and how dear they are to God. Furthermore, there is repeated emphasis that suffering, especially sickness, patiently endured remits sins (p.128).

Consequently, Bowker's (1970) perspectives can be seen to be acknowledging that the situational factors that impact on a sufferer's life have a direct link to the types of religious beliefs subsequently adopted. In this way, someone who suffers with a particularly challenging illness might be assumed to be closer to God than perhaps someone without an illness. Furthermore, caregiving in particularly challenging circumstances may be interpreted as awarding more rewards than caring in a less demanding situation. The ensuing section examines how distinctive themes emerged between the rewards that carers of children with learning disabilities described, and rewards that carers of relatives with physical disabilities or chronic illnesses described.

#### ***4.5.1.4 Rewards Depending on who Within the Family is Being Cared for***

Respondents' religious perspectives pertaining to their caring role was further complicated by their relationship to those being cared for. In this



way, two distinct themes emerged, which revealed that a carer's religious beliefs about the undertaking of care were dependent upon the type of disability affecting the individual requiring care. Firstly, caring for a relative with physical disabilities was perceived to be a test from God to wash away the sins of the afflicted, or award the opportunity to demonstrate steadfastness to God (Ahmed, 2000). Consequently, the sacred nature of the carer's role within these circumstances was in the general performance of care. Secondly, perceptions about caring for a relative (usually a child) with learning disabilities were substantially different. Here, respondents reported that the individual being cared for was a gift from God to test the carer's patience and steadfastness in the face of their challenging situation. As such, relatives with learning disabilities were not regarded as being tested. Instead they were often attributed with spiritual significance, with some even reporting that they considered them to be an 'angel'. These findings are discussed below.

Tanweer cares for her husband in the advanced stages of Multiple Sclerosis. She has cared for him for twenty years and has watched his physical decline to complete confinement to his bed. He has nearly died on a number of occasions and she described the past two decades as an 'emotional rollercoaster'. However, she describes the spiritual significance that she places on her husband's disability and her caring role within this as being very comforting for her. In the quote below Tanweer explains that being afflicted with an illness like Multiple Sclerosis or cancer is a way of God washing away ones sins before

dying. However, she also weaves the role of the carer within this explanation to describe the sacred nature of her role as his carer:

*Qur'an* says that it is from *Allah*, from God and especially if you are in an illness like [husband] or a cancer patient, we say it is like, eh, God is washing away your sins, that is why he has given you this because he wants to purify you before taking you away. That's what it says. It also says that if you visit a sick person, if a person was to visit another sick person, it is said that if you go in the morning, like seven thousand angels would pray for your forgiveness until the following morning. And if you were to go in the evening, then obviously until the next evening. That's how virtuous it is to attend to a sick person. So to look after a sick person, eh, it must be huge. And to be a sick person, obviously as I said, it is like a forgiveness of your sins.

Echoing Tanweer's perspectives, Ahmed (2000) argues that in Arabic, a person who is 'sound and healthy is said to be *salim*' (p.31). In Arabic dictionaries, the word *salim* is defined as 'the one who has been stung or bitten' (ibn Daqiq al-'Eid, 1983, cited in Ahmed, 2000). Ahmed explains that in pre-Islamic Arabia, a snake bite was regarded as a good omen, foretelling a good future. Consequently, Muslims began to understand being in a healthy state of *salim* as being able to see the will of *Allah* even in times of adversity (such as being bitten by a snake). Ahmed concludes that *salim* or 'health' does not regard illness as a punishment but rather as a 'test' from *Allah*. As such, patience and faithfulness in times of illness and tragedy will afford the individual

rewards from *Allah*. Some Muslim scholars argue that the greater the illness, the greater the reward. Beliefs such as these may be seen as a comfort to the respondents' in their sometimes challenging caring circumstances. In this way, embracing some of the popular Islamic beliefs about care, illness and disability may be seen to be a process of meaning making about circumstances beyond their control.

Dhami and Sheikh (2000) also address popular Islamic beliefs pertaining to the family in their informative contribution to Sheikh and Gatrad's (2000) *Caring for Muslim Patients*. They argue that the family unit is revered within Muslim cultures. Elderly parents are respected on the grounds of their life experiences and hierarchical position within the family. Consequently, the opportunity to care for an elderly parent is perceived as a gift from *Allah*. These perspectives were regularly voiced within the accounts given by those caring for a parent or parent-in-law. For example, Nisha explained that within Islam the opportunity to care for ones parents awards 'big' rewards.

Islamically, to look after our parents is a really big reward for us. To respect our elders and to be patient. Being a carer is something very difficult and it teaches in our *Qur'an* that to look after someone, if you can get through that then there is a very big reward and we all know that (Nisha cares for her elderly father with physical disabilities).

Nisha's response acknowledges the difficulties of undertaking care. Her belief in the rewards to come may provide her with meaning for the difficulty or suffering that may be endured in the process of care.

Foziah alludes to the hierarchical nature of undertaking of care within Muslim families that Dhami and Sheikh (2000) address by explaining that caring for her elderly mother is a religious duty.

[I]t's not that we doing a favour or – I couldn't call it a duty you know as such, but she is our mother, she is our responsibility and we have to do it – religiously we have to do it for her. Because when we were little, I mean she did everything for us, why not? It's our turn to do it in return now. We have to do it (Foziah cares for her elderly mother who suffered a stroke ten years ago which left her with physical disabilities and visual impairments).

Perceptions of caring for a family member with learning disabilities were distinctly different from the perceptions of caring for a relative with a chronic illness or physical disability. Here, beliefs strongly supported the perception that an individual with learning disabilities was sent to the carer as a gift from *Allah* to test the respondents patience and steadfastness. Ghaada cares for her daughter with learning disabilities and also cared for her son with learning disabilities and challenging behaviour until he was taken into a care home. She explained that she felt happy that *Allah* had given her these children because it made him happy to see that she was caring for them:

[O]ur faith in God is that he predicts our life and our future. In that way you don't feel upset, you feel happy because you are pleasing God because he has given you this child and you are looking after the child.

Similarly, Amina and Umina described their disabled children to be sent from *Allah*. Amina also described her son with learning disabilities as a 'gift'. The description of a child with disabilities as a 'gift from God' was voiced by many of the carers in the study.

Amina: [The *Qur'an*] say that it is a gift from the God, that you have got a special child and you must look after him. The more you look after him then there is benefit (Amina cares for her son with learning disabilities).

Umina: If you have got a disabled child then they are more blessed than we are, definitely. So we shouldn't be unhappy, we should be happy. If you have got a child like [daughters name], God has given it, so you don't ignore it. It is a gift from God. You can't do anything. You have to look after it if we are here, until we are gone and then someone else will look after them. That is what Islam says. You don't ignore kids like these (Umina cares for her daughter with Down's syndrome).

Umina touches on the 'blessed' nature of a child with a disability like her daughter's. This is discussed in more detail by Eshmaal, who describes her daughter as an 'angel', 'pure' and a 'lucky charm'.

In Muslim, we say that if you have a child like this they are angels for us from God because they are innocent, they don't know the world is good or bad. [...] [H]er heart is very clean so we think they are angels from the God and we think that she is lucky for us, a good charm [laughs]. What do you say? A lucky charm?

The attribution of spiritual significance upon a child with learning disabilities was a prominent theme within the data. Carers used words such as 'pure', 'special', 'blessed', 'angels' and 'clean' to describe the children being cared for. The perception of a child with disabilities as being spiritually significant has not been explored in relation to Muslim families, however, it has been briefly touched upon by researchers focusing on other faith groups. Bennett *et al.* (1995) in their study of Christianity and children with disabilities found that specific religious beliefs were articulated by the respondents in their study, whereby a child with a disability was often perceived as a gift from God. They interpreted these beliefs as having a significant impact on a parent's ability to cope with their situations.

Responses that adhere to Weber's first pure type solution to the problem of theodicy were of particular significance within this research. Participants generally perceived their caring role to be a preparation for a rewarding afterlife. As the above discussion demonstrates, the belief in an omnipotent God allowed the respondents in the study to trust that their difficult circumstances had divine intentions that would be ultimately reconciled in the afterlife. This provides a solution to the

problem of theodicy in a manner that was comforting to the majority of the respondents.

The following subsection addresses how some respondents also presented accounts that adhered to Weber's third pure type solution to the problem of theodicy, or *karma*.

#### **4.5.2 THIRD PURE TYPE SOLUTION TO WEBER'S PROBLEM OF THEODICY: *KARMA***

Weber (1922) regarded the Hindu doctrine of *karma* to be the most complete solution to the problem of theodicy. *Karmic* principles perceive that good fortune and suffering are awarded on the basis of good or bad behaviour. Consequently, the responsibility of suffering is placed squarely with the individual. As such, Weber perceived it to be the most rational of all possible theodicies (see section 2.2.2 for a more detailed discussion of this). Although the doctrine of *karma* is most popularly associated with Hinduism, Weber (1922) argued that all theodicies may be measured by their approximation to the three pure type solutions. As such, the adoption of *karma* by the respondents in this research refers to the philosophy, rather than the religion of the Hindu doctrine.

Sharma (1973) analysed the application of Weber's theories of theodicy in practice by investigating the doctrine of *Karma* in her ethnographic study of a Hindu Himachal Pradesh village. She argued that if an individual accepts the doctrine of *karma* then the need for a theodicy

will never arise as all suffering is the result of past sins committed. From this perspective, no suffering can be perceived to be unjust. However, Sharma warns that Hindus do not necessarily hold to scriptural beliefs about *karma*: 'Individuals may reject certain 'orthodox' beliefs, or at any rate adhere to modified beliefs or idiosyncratic interpretations of these beliefs' (p.350). The findings from Sharma's study provide an interesting context to how the respondents in this study presented *karmic* beliefs. This is examined below.

Some respondents presented beliefs that pertained to Weber's third pure type solution to the problem of theodicy in that they applied aspects of *karmic* principles (that rewards and suffering are the result of individual moral and immoral actions) to their religious explanations of their caring role, however, this was only partly embraced. As such, the prospect that their caring circumstances were ultimately self-inflicted was not cited within the accounts presented during the interviews. Instead, respondents employed *karmic* principles, which aligned with Weber's third pure type solution to the problem of theodicy to illuminate the spiritual significance of their caring role. Parvina employed *karmic* principles to explain how the undertaking of care will be rewarded in the afterlife.

*Qur'an* teaches us to look after them very well, [...] don't tell them off, keep the child happy, also in return for this; when you die, it will be easy for you, you will have an easier death. You will get rewarded in your life after death (Parvina cares for her son with Down's syndrome).



Similarly, Yalina presented aspects of *karma* in her explanation of how she perceives the religious dimensions of her caring role:

[I]f you do bad with someone, you get bad. So if you are caring for someone with a physical or learning disability and you are not looking after them properly and they are suffering in some way then you are not doing good for them and you will get a bad reward for that. But if you are going to do good for someone then you will get good.

Parvina and Yalina's accounts suggest that although some of the respondents in the study adopted aspects of *karma*, or Weber's third pure type solution to the problem of theodicy, this undertaking was somewhat incomplete, complex and included aspects of Weber's first pure type solution to the problem of theodicy (that suffering would be ultimately reconciled in the afterlife). Sharma (1973) also found that the Hindu villagers in her study presented mixed beliefs. She argued that even though *karma* provides a complete solution to the problem of theodicy in theory, it was not always employed by the villagers to explain their suffering. For instance, a chronic illness or ailment that did not respond to treatment was often attributed to the sorcery of another kinsman. The sufferer would then consult a ritual specialist who would attempt to detect the origin of the trouble and prescribe protective charms or amulets.

Sharma (1973) concluded that the kind of answer that *karma* provides to the justification of suffering might intensify psychological distress

rather than alleviate or comfort the sufferer. Consequently, the individual is afflicted by both suffering and guilt. Instead, the villagers in her study combined these philosophies with other beliefs that existed alongside, in both logical and illogical ways, to deflect the fatalistic blame that *karma* places on a sufferer. Sharma argues that we cannot expect religious adherents to act in accordance to scriptural statements. Conversely, one should observe how religious belief operates within the total belief system of its adherents:

We cannot understand the meaning of a particular belief if we depend only upon scriptural statements, or any other cultural expression of creed, until we have discovered its position in the total belief system of its adherents and seen how it operates in its social context. If we expect the sacred literature on Hinduism to supply us with the context of beliefs we are expecting something which it cannot provide and are liable to further confusion' (p.349).

These theories may contextualise why only certain 'pure type' solutions that Weber (1922) presents to explain suffering seemed to be adopted by the carers in this study. For example, Weber's second pure type solution to the problem of theodicy (the battle between good and evil) would have required the respondents to report that they perceived their caring situation to involve some form of evil. As Sharma suggests, employing religious beliefs that take on a potentially negative perspective may be psychologically distressing, and as a consequence

undermine the positive reinforcements that many of the respondents in the study reported receiving from their religious beliefs.

These theories are supported by the findings in this research, whereby carers regularly presented negative accounts of how disability was perceived by others within the Muslim community, but not by the respondents themselves. These issues are discussed in more detail below.

#### **4.5.3 EXPLORING ‘OTHER PEOPLE’S’ NEGATIVE MUSLIM PERCEPTIONS OF CARE, ILLNESS AND DISABILITY**

As the above two subsections have demonstrated, the respondents in the study tended to adopt and construct beliefs that provided positive spiritual meaning to their often demanding caring circumstances. Consequently, these accounts predominantly aligned with Weber’s first pure type solution to the problem of theodicy. These arguments were reinforced by how the respondents presented beliefs pertaining to Weber’s third pure type solution to the problem of theodicy (*karma*). Here, respondents tended to exclude both negative beliefs about their caring situation or the illness or disability of their cared for relative/s. However, some participants described how ‘other people’ within the Muslim community negatively regarded being disabled or being a carer. Some even described how they had personally experienced verbal abuse from such individuals. In addition to this, several professionals interviewed for this research spoke about how some of the Muslim

carers they supported held negative beliefs that they attempted to dispel as part of their occupational role.

The theme presented within this subsection is undertaken with some caution as none of the carers reported holding negative theodicies about their own caring circumstances, or of the illness or disability affecting their cared for relatives, however, some participants reported 'other people' within the community holding these views. This finding was also observed in Poston and Turnbull's (2004) research on the role of spirituality for families with a child with disabilities. Although many of the respondents in their study reported perceiving their caring role as a test from God, or the disabled child as a gift from God, none of the participants explicitly reported that they 'perceived their child as God's punishment for some perceived failure on their part' (p.103).

These findings may also indicate a methodological point. The majority of respondents in this study were sampled from one of four specifically Muslim carers' organisations (see section 3.5 for a description of each organisation). Their professional role often included educating carers about the medical aspects of disability and illness, and dispelling some of the more negative spiritual beliefs that some professionals in the study reported their service users describing. In this way, the respondents may have been telling me what they thought they should say rather than what they actually believed. Gardner (2002) observed similar findings in her anthropological study of Bangladeshi migrants to

Britain. Here, she surmises that the accounts of sickness and disability that her participants presented may be attributed to ‘what they thought would be most suitable for my English ears’ (p. 186). Furthermore, she explains that her respondents were often so surprised that she knew about terms such as *Bhut* (evil eye) and *jinn* (possession by a spirit) that they often did not recognise the terms at first. However, many of her respondents subsequently spoke about how they did invest belief in these explanations for illness and disability. Her findings echoed the sentiments in Kaleemah’s account presented below. Kaleemah works as a development worker for Organisation B (see 3.5.2 for a description of this organisation). She described how many of the Muslim carers she supports employ negative religious beliefs pertaining to the work of an evil spirit (*jinn*), to understand the challenging behaviours of their cared for relatives. Kaleemah was specifically selected for her professional role as she descended from Mirpur, Pakistan, where the majority of the organisations service users originated. During her interview she described how her knowledge of the region, its customs and culture, allowed her to be more supportive of the carers, especially in dispelling some traditional understandings of disability:

Most of our carers, if they are displaying challenging behaviour, they think that it is a superstitious thing and that person has got a spell on them and all these superstitious things which goes according to our religious beliefs. If they talk to me about that I know where they are coming from. I know that in the religion it says that you can do black magic, or they say that that particular person is possessed by some

unseen or by eh, a spirit, that's why they are behaving in a certain way. So, I know where they are coming from. I don't really believe what they say, but I know that happens, and to an extent it is a religious belief. But bearing that in mind I need to convince them that it is not what you think it is, it is this. Whereas if they spoke to somebody else about that then they would be like 'what's going on here?' Because I know that in Muslim religion, black magic happens, you know, to an extent, I don't really believe that you are possessed by an evil spirit or whatever [...]

It's not one particular carer, it's many carers dealing with a learning disability. Even if they have got a learning disability, they don't understand the terminology of learning disability. They think that they are possessed by an evil spirit, or black magic of some sort. But then, it's giving them the awareness of learning disability, that it is an illness you know, not curable, but you know it happens.

In support of Kaleemah's claims, some scholars have argued that disability is regarded as shameful within some Islamic communities and societies. Turmisani (2001) argues that in the *Qur'an*, icons of Islamic enemies are repeatedly portrayed as having physical disfigurements. Additionally, she describes how disability has been classically interpreted as being the work of evil spirit or *jinn*. Consequently, the birth of a disabled child brings shame and blame on the family, especially the mother (p.74). These findings are also shared by Gardener (2002), who describes how the Bengali Muslim respondents in her study attributed illness to a range of factors including possession of spirits (*jinn*) or evil eye (*bhut*).

Although these views were not directly expressed by the carers interviewed in this research, some respondents described the Muslim community being 'behind' or ignorant about disability, especially regarding learning disability in particular. This was most saliently described by Vardah, who cares for two adult daughters with learning disabilities.

As far as I can tell, our religion teaches us kindness and caring and understanding, but not everyone implements that, I mean in even in this religion they don't implement it. Because a lot of it is what they are just brought up with the religion, they don't know the background. It is a lot of knowledge you see, you have to learn knowledge and I find that even the Muslim people they don't know the knowledge a lot of it. I mean I am still learning myself at my age. So you have to learn things about your own religion, see what your prophet has to say. When I read about what he says, I mean he always used to help the needy, the disabled, he would help them first then the other people. But a lot of our people, they don't do that. There is a lot of ignorance there.

Similarly, Dunia argued that she felt that the Muslim community was behind in supporting families who care for relatives, and that the family often places additional pressures upon carers (these issues are discussed in more detail in Chapter Six):

I feel coming into this community that I have gone thirty years back [...] I think it is their culture, [...] some of them maybe see it as a burden looking after a child or being a carer but some do find it blessed but

[...] because of the responsibility of the family, I think that puts pressure on them. I have given a talk with [carers' organisation] with an audience, [...] I wanted to say my bit that it is very important as a carer, [...] it is a blessed thing. Don't be ashamed of it (Dunia cares for her son with severe learning and physical disabilities).

Meena and Shereen explore the negative perceptions of disability that Dunia alludes to in more depth. They both reported knowing people who would not leave the house, or attend social gatherings with their disabled children. Both these respondents described how they did not share these perspectives and regularly go out and socialise with their disabled relatives.

Meena: I know people who have got disabled children and when they go to weddings or any family gatherings or occasions, you never see them [...] I feel proud, my child is God's gift so yeah, I just take my child with me, wherever I go. All the time he with me, at the wedding or the town centres, everywhere (Meena cares for her son with physical and learning disabilities).

Shereen: You know some Muslims, there are very backwards and they don't want their children to go out. You see for me, I'm not scared of anybody. If they tell me I can't do this or that, I say 'what do you mean I can't?' Because he is my son I can do whatever I want. I don't care what they say to me but some people they worry so they just keep them in the house. So this makes it worse then. It has happened so many times before. My husband went to Africa to visit his mother and



[my son] needed to be taken out every day and this man says to me 'this is a man's job, it is not a woman's job!' and I said 'I don't care whose job it is' (Shereen cares for her adult son with learning disabilities).

In the accounts presented above, Shereen also describes an experience with a man who complained that she should not be taking her son outside due to it being a 'man's job' rather than a 'woman's job'. Meena also provided a similar story of how she has received complaints from people passing her in the street about showing her son in public, although it was unclear how many times this had happened:

Two or three people have said to me 'why you bring him outside with his tube?' [...] 'Why you bring the boy outside?' I say 'why? What's wrong?' and they say 'now look, he has a tube [in his nose], some people are looking and scared' [...] I say 'he looks like a normal boy. He's not dribbling, not tongue out, not looking funny. My boy, he is very good looking, just tube in. When that lady says [what she did to me], I was very upset, I go mad really. That time I say 'that's not your business'.

Unlike Sharma's (1973) research, this study was unable to include the perspectives and theodicies of individuals in the Muslim community who did not care for a relative, or who were not currently affected by some significant form of suffering. Some of the professionals interviewed for the study were not carers, but all had a particular interest in improving the lives and circumstances of Muslim people with disabilities and their

carers. As such, outsider perspectives of disability and care could not be accounted for, apart from the subjective accounts of the carers and professionals interviewed for this study. This would be an interesting consideration for further research and is discussed in more detail in Chapter Seven. These subjective accounts, however, suggested that 'others' may hold fundamentally different perspectives on the undertaking of care and the affliction of an illness or disability on a family member.

Sharma (1973) reported that the Hindu villagers in her research often held different perspectives of why an individual was suffering to the sufferer herself. For example, 'Sibbi' suffered from a skin disorder that was not responding to dermatological treatment. Her neighbours explained the ailment as a punishment from a deity she had offended, and her ailment was therefore her responsibility and fault. However, 'Sibbi' explained her suffering as the work of her daughter-in-law's sorcery. 'Sibbi's' explanation removed her from any direct moral responsibility. Sharma concluded that even though the principles of *karma* provided a logical solution to all suffering, the villagers combined these philosophies with other beliefs that existed alongside, in both logical and illogical ways, to deflect the fatalistic blame that *karma* places on a sufferer.

These theories may also be applied to the findings in this research. As a carer, to regard disability or caring as an embarrassment or shame

may be incongruous to a healthy psychological coping strategy. These findings are particularly interesting when compared with the findings of researchers of Muslim family carers in other countries, especially some Islamic societies. Here, the themes of stigma and shame factor significantly both within general society and within the domestic sphere, the latter contrasting with the findings in this study (e.g. Ashtan, 1997; Duvdevany and Abboud, 2003) For example, Ashencaen Crabtree's (2007a; 2007b) work on parents of children with developmental disabilities in the United Arab Emirates reveals the negative consequences associated with caring for children with learning disabilities. Here, she argues that discrimination of people with disabilities is experienced both at a societal level and within the domestic sphere. Echoing findings in this study, Ashencaen Crabtree (2007a) explores her respondents' accounts of experiencing ignorance and intolerance of the general public towards their disabled children arguing:

A Palestinian mother described how her premature baby was removed from the incubator after only three days once it was realized that he had Down's syndrome and hence a life not worth saving. Other parents gave examples of reactions from the general public that could be considered at best insensitive and at worst an indictment of ignorance and intolerance (p. 56-57).

In this study, Warda, who cares for her adult son with learning disabilities shared a similar account, where, on the birth of her son in

Turkey, she was told by the doctor not to pray for him because he was disabled. These experiences eventually led her to move to Britain as she hoped to receive better healthcare for her son.

We were all praying and the doctor said 'why are you all doing this? He won't be able to see, to walk, he won't be able to do nothing because he has a lot of problems'.

In contrast with the findings in this study, Ashencaen Crabtree's (2007a; 2007b) research also revealed how stigma and shame was also experienced within the domestic sphere, leading to at times dramatic consequences for the mother. Here, mothers may be 'repudiated by their husbands and non-disabled siblings' (2007a: 53). Additionally, she found that Fathers were more likely than Mothers to experience intense feelings of shame and disappointment. Boukhari (1997) echoed these findings in her study of working Mothers of children with learning disabilities on Lebanon. Her study revealed the sometimes shocking domestic abuse experienced by children (especially girls) with learning disabilities and their mothers.

[T]he birth of a disabled child is seen by many as not only a misfortune, but as shameful and embarrassing. The husband's family is likely to blame the misfortune on the mother: 'it is her [family's] bad seed...' In addition to bringing shame on the family, the birth of a disabled child is likely to consign his or her mother to a lifetime of misery, since the belief in this mother's culpability is used to justify a lack of practical and

emotional support to the child and mother on the part of the husband and extended family (p.37).

Boukhari's (1997) observations included how violence and sexual abuse within the domestic sphere was often considered by the fathers of children with learning disabilities to be an acceptable consequence of the shame and stigma brought on the family.

The findings in the studies above contrast with the findings in this research. Although the carers in this research did argue that their British Muslim community often held discriminatory attitudes towards disability, they were also often active in attempting to challenge these perspectives. Perhaps this was due to most respondents being affiliated with a carer group that was active in challenging negative perceptions of disability and improving the lives of Muslims with disabilities and their families. As such, most seemed dedicated to expressing the positive religious interpretations of experiencing illness, disability, and being a carer. This may have provided the carers with optimistic and beneficial coping strategies. For example, Dunia argued that it is the duty of all Muslims to show 'true Muslims' rather than the 'bad Muslims'.

Well I think that as a Muslim [...] it's our duty to go out there and show the true Muslims, not the bad Muslims. They need to go out and do their duty, which I don't see in my Muslim community. As a Muslim woman I think that it is their duty to go out and show what it is all about (Dunia cares for her son with severe learning and physical disabilities).

Many carers and professionals in the research echoed Dunia's opinions, and I often felt like many respondents in the research were using the interview as a platform to voice their political perspectives about both their community, and the needs of Muslim family carers (see also section 3.6 for a methodological discussion of this issue).

#### **4.5.4 SUMMARY**

This section explored the complexities of the religious beliefs that the carers in the study adopted to explain their caring situations. Weber's (1922) theories of theodicy were employed as a theoretical framework to explore how detailed theodicies embraced by the respondents in the study adhered to Weber's first and third pure type solutions to the problem of theodicy. However, these beliefs were presented in incomplete and complex ways. In terms of the carer's eschatological beliefs, or Weber's first pure type solution to the problem of theodicy, respondents generally perceived that *Allah* was in control of their circumstances. As such, their caring role was interpreted as a test from *Allah* to demonstrate patience and steadfastness during difficult and challenging circumstances, which would be generously rewarded in the afterlife. Furthermore, the data suggested that a carer's spiritual beliefs about her or his caring role was dependant, at least in part, on the intensity of the caring role being undertaken.

The adoption of Weber's third pure type solution to the problem of theodicy, or *karma* by the respondents in the study was arguably more complex. Here, respondents tended to adopt beliefs that supported the

notion that their caring role would be rewarded with good *karma*, which overlapped in some respects with Weber's first pure type, and excluded some of the more fundamental principles of *karma* which implicates the individual in their circumstances of suffering. This was explored in more detail by examining how the carers in the study perceived other people's perceptions of illness and disability. This suggested, like the findings in Sharma's (1973) research, that people who are not affected with some form of suffering may hold alternative perspectives to the sufferer herself. These suggestions need exploring in more depth with further research. This is discussed in more detail in Chapter Seven.

The significance that this analysis contributes to existing knowledge is that it makes an important point about how care was perceived by the Muslim family carers in the study. Consequently, a process of accepting and rejecting certain religious beliefs led to the majority of the carers in the study constructing intricate and detailed theodicies that supported and legitimised their caring role as a spiritually important undertaking. The findings in this research echo a growing body of literature that values how religious beliefs are 'lived' (McGuire, 2008) or experienced in everyday life. These ideas were examined in detail in Chapter Two (see section 2.2.1.), and frame the following section, which examines the 'lived' experience of faith in the carers' everyday lives.

#### **4.6 LIVED RELIGION: CARE AS RELIGIOUS PRACTICE**

The previous two sections in this chapter explored how being Muslim formed a salient aspect of the respondents' identities, and how detailed religious beliefs or 'theodicies' about the nature of care, illness and disability served as a positive and comforting aspect of a carer's perceptions about their often difficult and demanding circumstances. This section explores how the respondents' religious beliefs intersected with the lived practices of day-to-day routines of caregiving. Here, respondents regularly spoke about how their caring role took on spiritual dimensions, as a form of form of worship that compensated for, or replaced the need to perform popular Muslim practices such as praying five times a day (*Namaaz*) and going on pilgrimage to Mecca (*Hajj*). Furthermore, Muslim practices were often unfeasible for the cared for relative due to the nature of their chronic illness or disability. Consequently, respondents' also regularly reported that the spiritual dimensions of their caring role compensated for this. These 'embodied practices' have been at the centre of how Meredith McGuire (2007; 2008) explores the 'lived' constructions of everyday religion, and are the focus of this section.

McGuire (2008) argues that daily routine practices can take on spiritual dimensions over time. She asserts:

Daily life is filled with routine practices – ways of doing tasks, of walking and sitting, of talking and gesturing, of showing emotions and so on. Although the tasks, the walking, the conversation, and the like are typically practical ends, the practices themselves can, over time,



effect physical, emotional, and spiritual developments for people who engage in them (p. 13).

As articulated in Chapter Two, explorations of the private, individual and everyday experiences of religion are relatively new. Pace (2007) argues that the role of religion has changed within contemporary society. In his study of Catholicism in Italy and Spain, Pace explores how the Catholic Church continues to play an important public role in both Italy and Spain, however, increased individualisation has meant that religious adherents are increasingly claiming the 'final decision' on the precise institutional 'codes' of how religious beliefs are practised in everyday life. In this way, Pace argues that the role of religious institutions have changed rather than necessarily declined.

Pace's (2007) arguments are echoed within the findings in this research, where Muslim religious practices constituted an important aspect of what being Muslim meant to the respondents, even if their demanding caring circumstances prevented them from fulfilling these obligations. Leila cares for her husband with physical disabilities and her daughter with learning disabilities. She explained how she felt unhappy that her caring role prevented her from performing her five prayers a day (*Namaaz*), as she believed that she would be questioned on 'judgement day' about whether she had performed her prayers:

Interviewer: The only thing that she<sup>19</sup> feels unhappy about is that she misses her daily prayers. We have to pray five times a day.

Interviewer: Is being a Muslim very important to you?

Leila: Yes.

Interviewer: Can you tell me a bit more about what it means to you?

Leila: It is very important. It is a way of life. As a Muslim I am aware that after death, on judgement day, one of the questions that will be asked is did I do my prayers? And things like that. I know I will be asked about what I did in my life here so obviously it is important to me because I have got to answer back to *Allah*.

Many carers in the study echoed Leila's concerns, describing how their caring role prevented them from fulfilling expected Muslim religious practices such as praying five times a day (*Namaaz*), or going on pilgrimage to Mecca (*Hajj*). However, a salient theme emerged from the data, whereby respondents' often perceived that their caring role constituted a form of worship, and therefore substituted the need to perform certain Muslim religious obligations. These beliefs echo both Pace (2007) and McGuire (2008), whereby institutionally ascribed 'codes' of how religious belief should be practised intersect with the lived circumstances of everyday life. Here, ascribed religious practices

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<sup>19</sup> Leila's interview was carried out with the use of an interpreter. As such, some passages of her transcript appear in the third person.

are reconstructed to fit the situational circumstances of individual religious adherents. McGuire (2008) argues that by valuing what individual people 'count' as religious practise, one can effectively link the material aspects of people's lives with the spiritual.

This cognitive process is demonstrated by Yalina, who cares for two young children with severe learning and physical disabilities. Yalina belongs to Organisation B<sup>20</sup>, and is known throughout the group as having a particularly demanding caring circumstance. Her interview had to be rescheduled on numerous occasions, and when we finally met, she described how she thought that it was 'wrong' that she did not perform her daily prayers (*Namaaz*), or do her readings. However, she reconciled this by arguing that her demanding caring role may compensate for this.

Sometimes because I think I'm doing good for my children, if I am missing my prayers, I'll probably get a bit of good luck or good reward because I have at least been caring for my children properly. That is how I see it but I am still wrong because I don't get the chance to pray, to do my prayers and my *Namaaz* or my readings like that. Then again, I think where am I supposed to get the time to do that? Because if I get up at half six and I go to bed at one then I don't get the chance!

In this way, Yalina reveals the cognitive processes through which she reconstructs institutionally ascribed religious practices with the lived

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<sup>20</sup> See section 3.5.2 for a description of Organisation B.

circumstances of her daily life. She reasons with the practicalities of her day-to-day caring situation and concludes that she is unable to include performing her daily prayers. Consequently, she reconstructs her belief system to bestow spiritual significance on her caring role. As Pace (2007: 45) argues with reference to the practice of Catholicism: '[i]ndividuals claim the final decision on the precise contents of this [institutional religious] code, increasing the range of conduct that falls outside the official system of belief. Generalized Catholic symbols provide a collective memory but are no longer directly linked to predictable social actions'.

The reconstruction of Muslim religious practices was a common theme within the data. For example, Fuseelah cares for her daughter with mild learning disabilities. She described how her caring circumstances mean that she is unable to go on pilgrimage to Mecca (*Hajj*). Performing *Hajj* is one of the five pillars of Islam and is therefore obligatory for all adult Muslims who can afford to undertake the journey and are in good health (Gatrad and Sheikh, 2005; Hussein Rassool, 2000). Similarly to Yalina, Fuseelah bestows spiritual significance on her caring role, which removes her from feeling like her caring role prevents her from fulfilling obligatory religious practices. She asserts:

Like Muslims have to go to pilgrimage, on *Hajj*, which is one of the pillars of Islam but obviously because of [my daughter] I can't go on my own so in my religion it says caring is like performing a *Hajj*. Even if I

can't go because of her, I still get the same blessings because I have not been able to go because of caring for her.

In this way, institutionally ascribed Muslim religious practices formed the basis of Fuseelah's belief system, however, this could be adapted, embellished and reconstructed to account for the lived circumstances of her caring role. As Levitt (2007: 109) observes of modern religious practices: '[R]eligion does not stay inside the walls of official religious buildings. Private, informal religious rituals often reveal much more about the changing nature of religious life than what goes on at the church or at the temple'.

The respondents' cared for relatives were also often unable to undertake Muslim religious practices due to the nature of their chronic illness or disability. Here, respondents described how they would take on their cared for relatives religiosity as part of their caring role. For example, Tanweer, who cares for her husband in the advanced stages of Multiple Sclerosis, described how she turned her husband's bed towards Mecca five times a day so that he may continue to perform his daily prayers (*Namaaz*). Similarly, Foziah described how she gives money to charity because her mother is unable to perform her prayers:

Well at the moment because Mum, she can't say her prayers or anything, so we do whatever we can, like giving money to charity is a prayer in a way, so we do and try to give as much charity on my Mum's behalf. And eh, we say her prayers for her as well you know (Foziah

cares for her mother who suffered a stroke ten years ago which left her with physical disabilities and visual impairments).

Bartowski (2007), in his study of evangelical Christian families argues that social actors use faith as a tool for solving the problems and dilemmas of family life. The evangelical women in his study were not cultural 'dupes' to the patriarchal faith with which they are affiliated, as previous research has assumed them to be. Instead, they possessed the ability to construct gender and religious identities marked with 'fluidity and nuance' (p. 154), and were strategic in their motivations for affiliation. As such, Bartowski argues that:

Social actors, even those who share a common religious affiliation, may use the tools of their faith in diverse ways to solve the dilemmas presented to them by family life. In the end, the complex and even contradictory linkages between religion and family present scholars with challenges that are at once existing and daunting (Bartowski, 2007: 165).

Bartowski's (2007) observations of the usages of faith to solve the dilemmas and problems of family life are echoed within the findings in this research. For example, respondents' of children with learning disabilities regularly spoke about how they encouraged their cared for relatives to engage in Muslim religious practices. However, due to the nature of their learning disability they were often unable to undertake these expectations. In response to this, participants spoke about how

the spiritual nature of their caring role compensated for this. Like the religious theodicies discussed above, these fluid constructions of religious belief allowed respondents to positively perceive their families as practising Muslims, even when institutionally ascribed religious practices are not possible. For example, Enisa cares for her daughter with learning disabilities. She argued that even though she encourages her daughter to engage in religious practices, her inability to perform these tasks is religiously justified because of her disabilities.

I tell my daughter that she has to fast now. She says 'OK, OK, I am fasting now', and then I catch her eating. My daughter eats during Ramadan, but because of her disabilities it doesn't count. She is different.

Like Enisa, Dina cares for her son with severe autism. When she was asked about her son's religiosity she described how he would break certain religious observances such as fasting during *Ramadan*, and question the existence of *Allah*.

He says that he is fasting and then it gets to twelve o'clock and he says 'that's it. I have fasted! Today I have fasted half day and tomorrow I will fast half day!' [laughs] Then he says 'why [are] you fasting? Why do you have to do it? What is this God? Tell him to come and see me! Why does everybody see *Allah*, *Allah*, I want to see him! Is he hiding somewhere? We never see him' [...] Once his father take him to the Mosque he hit his head on the floor when he was praying.

He does it every time, because he can't do it slowly, he'll just bump his head on the floor (Dina cares for her son with severe autism).

The inability of Dina's son to take on certain religious duties as a practising Muslim seemed to be reflected in her subsequent religious perceptions of disability. In this way, she argued that disabled people 'don't have a religion', and similarly to other carers in the study, that her care of him substituted his need for religious observance:

Disabled person, they don't have a religion. We look after them and that is their religion. My son, he knows he can pray but he does not go into the meaning of it.

This process of legitimising the lack of religiosity of a cared for relative due to learning disabilities seemed to be undertaken by other carers in the study. Ghaada described how people with learning disabilities are not expected to practise their religion:

[I]n our religion, people who are insane, who are not normal, healthy thinking people, the religion side of things are not put on him. It is not put on him to fast or to pray because they do not have the mentality to do it, or to go to the Mosque. But because he [son] is brought up in the religion, he knows who is God, [he knows] who is *Allah* (Ghaada cares for her daughter with learning disabilities. She also cared for her son with learning disabilities and challenging behaviour before he was taken into a care home).



The extracts above, sampled from Enisa's, Dina's and Ghaada's interviews, demonstrates how Muslim religious beliefs could be reconstructed to fit the lived circumstances of everyday life. Here, some carers of children with learning disabilities could legitimise their cared for relatives lack of religiosity by reasoning with the fact that they are unable to take on certain aspects of religious observance. These findings provide further strength for Pace's (2007) arguments, whereby religious adherents have the 'final say' on codes of institutionally ascribed religious practices.

Ammerman (2007: 224) argues that when researchers declare that belief has declined, they are telling only a very small part of the story. What the contributors to her edited book, and the findings in this research suggest is that religious belief continues to play an important and significant role in the lives of individual people. However, the nature of this role may have shifted (see also Davie, 1994; Pace, 2007). What the findings in this study suggest is that institutional religious practices formed the basis upon which respondents constructed meaning around the lived practices and circumstances of everyday life. In this way, the respondents bestowed spiritual significance on their caring role as a means of accounting for missed Muslim religious practices such as praying five times a day (*Namaaz*), and going on pilgrimage to Mecca (*Hajj*).

## 4.7 CONCLUSION

The findings in this research suggested that being Muslim formed an important and significant aspect of the respondents' identities, which were regularly presented as complexly entwined with their role as a carer. In this way, participants offered detailed religious beliefs pertaining to the illness or disability of the cared for relative and their role as a carer. In response to these findings, Weber's (1922) theoretical contributions to the concept of theodicy, was applied as a framework for exploring how the carers in the study constructed religious beliefs about their often difficult and demanding caring circumstances. These beliefs generally aligned with Weber's first and third pure type solutions to the problem of theodicy in complex, incomplete and interrelated ways. This analysis revealed the importance of religious beliefs that positively support the individual rather than incite blame or guilt.

Respondents also regularly spoke about how religious beliefs intersected with the day-to-day practices of caregiving. Here, institutionally ascribed Muslim religious practices were reconstructed to give spiritual meaning to the lived circumstances of everyday life. Due to the often demanding nature of a carer's situation, performing Muslim religious practices such as praying five times a day (*Namaaz*) and going on pilgrimage to Mecca (*Hajj*) were often not viable. As such, respondents regularly described how their caring role took on spiritual

significance, which served as a substitute for the missed religious practices of both themselves and their cared for relatives.

This chapter reveals the importance that respondents placed on perceiving that they were living religious lives. These findings provide further support for the growing body of literature that values the lived and everyday experiences of religion, challenging assumptions that belief is necessarily in decline. As McGuire (2008: 187) argues:

[W]hen we rethink what is religion, we need also to reconsider our conceptualisations of religious identity and commitment. Perhaps the borders of religious identity and commitment are as contested, shifting, and malleable as the definitional boundaries of religions. When we focus on lived religion, we come to appreciate that other aspects of identity and commitment, including ethnic, gender, and national identities, are equally complex.

Recognising the complex boundaries of living religious lives, as McGuire suggests, the following chapter explores how upholding and maintaining Muslim religious identities often affected how respondents perceived, experienced and negotiated state services.

# **CHAPTER FIVE**

## **PERCEPTIONS OF AND NEGOTIATIONS WITH STATE SERVICES**

### **5.1 INTRODUCTION**

Chapter Four explored how respondents perceived being Muslim as a significant and positive aspect of their identity. The importance placed on upholding and maintaining religious identities was saliently demonstrated by how the carers in the study reported accessing, experiencing and negotiating state services. This is the focus of the ensuing chapter.

Access to certain facilities of British state services was reported to be particularly difficult for some of the respondents in the study, in that they challenged and contradicted core aspects of the carers' religious and cultural identities. In response to this, participants regularly described certain services as dangerous, 'risky', and untrustworthy. Husain and O'Brien (2001: 15) argue that for 'South Asian Muslim communities in Britain, the importance of faith, family and community continue to be a challenge in a secular and increasingly individualistic society'.

In her classic work on *Purity and Danger*, Mary Douglas (1966) explores how social groups attempt to maintain ethnic identities by

applying symbolic boundaries which demarcate the 'purity' of the inside from the 'danger' on the outside. In this way, the rules and beliefs of the group are reinforced. The conceptual framework that these theories offer was employed by Judith Okely (1983) in her empirical research on the *Traveller-Gypsies*. As discussed in Chapter Two, Okely (1983) addresses the methods with which minority groups manage to retain their identity whilst residing alongside mainstream society. She argues that 'pollution beliefs' about mainstream society can reinforce an ethnic boundary for minority groups:

One way of remaining different is pollution beliefs which both express and reinforce an ethnic boundary. The Gypsies' beliefs not only classify the Gorgio [non-gypsy] as polluting, but also offer the means to retain an inner purity. If certain observances are maintained, the Gypsies can enter Gorgio territory unscathed (p.77).

Purity and pollution beliefs emerged as a salient theme within the respondents' perceptions of and negotiations with state services, in particular, social services. As such, Douglas's and Okely's concepts are employed within certain sections in this chapter to explore how carers reported managing, controlling and preventing access to certain facilities within British state services.

Perceptions of accessing and experiencing state services were primarily dependent upon two factors. Firstly, significant differences emerged in the carers' perceptions between health services and social

services. Respondents generally expressed few concerns about health services; however, social services were often seen to be particularly problematic. Secondly, the gender of the cared for relative emerged as a salient factor in how the perceived dangers and 'risks' of social services were negotiated (see section 4.2 for the biographical data of the respondents in the study).

This chapter is thus divided into two sections. The first section explores the respondents' perceptions and experiences of health services. As the respondents generally experienced these services positively, the conceptual theme of purity and danger does not emerge here.

However, it does provide important context to the second section, which explores how the carers in the study often perceived social services to be 'risky', threatening and dangerous, especially to females with learning disabilities. As such, this section is divided further into two sub-themes, which examine the distinct differences in the management of access to services between female and male disabled relatives. The first sub-theme examines how carers of females with disabilities often prevented access to social services to uphold 'purity' and avoid the risks these services posed to family honour (*izzat*). In contrast, the second sub-theme explores a different attitude to accessing services for males with disabilities. Here, carers did not prevent access to services, but managed and controlled aspects of social service facilities enough to uphold their Muslim religious values.

It is important at this point to clarify the distinction between health care and social care. Phillips (2007) argues that health or medical care is often difficult to disentangle from social care, however, due to the strengthening of both professions, divides between the two forms of formal care have become more distinct. Health or medical care is usually located within the National Health Service, and 'is characterized by doing things to the body, often invasive in nature' (Phillips, 2007: 127). Conversely social care lies within the scope of local authorities and is more nebulous. It refers to counselling, interpersonal work and day-to-day tasks. Phillips (2007: 128) argues that '[s]ocial care is often provided in situations that are not life-threatening, but it is important for survival, a pattern and quality of life'.

As discussed in Chapter Three, interpreters were used for some of the interviews with Muslim family carers. However, if respondents understood the question, they would often respond directly. Some passages of interviews carried out with interpreters are presented in the third person, and some in the first person. When a quote is presented in the third person, a footnote is added to provide clarification.

## **5.2 HEALTH SERVICES: PERCEPTIONS AND EXPERIENCES**

Much existing literature has mapped the ways in which South Asian carers often face barriers to accessing health and medical services. These studies tend to suggest that language barriers, and religiously

and culturally inappropriate services prevent access to health and medical care (e.g. Greenwood *et al.*, 2000; Hatton *et al.*, 1998). The findings in Katbamna *et al.*'s (2002) study suggested that GPs were often insensitive and lacked an understanding of carers' circumstances, which they argued could be interpreted as a form of implicit or explicit racism. The findings in this study contrast with this body of knowledge in that respondents generally reported positive experiences of accessing health and medical care. Furthermore, negative encounters were interpreted as being due to general incompetence of some professionals, rather than being due to racism or Islamophobia<sup>21</sup>. Additionally, respondents reported being satisfied with making alternative arrangements if health and medical facilities were unable to cater for religious and cultural requirements.

Although the main thrust of this section argues that the respondents in the study positively received health and medical services, some also presented accounts of negative encounters with GPs and hospitals. However, none of the carers attributed these experiences to implicit or explicit racism or Islamophobia. Moreover, respondents argued that ethnicity and religious affiliation was irrelevant to experiences of health and medical services. For example, Quaniah cares for her daughter with restricted mobility in her arm. She complained about how difficult it was to make an appointment with her GP, and attributed this to the receptionists at the surgery. However, she did not perceive this to be

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<sup>21</sup> Laird *et al.* (2007) warn that an increase in Islamophobia may have an impact on the experiences of health and medical services.



due to her being Muslim:

Quaniah: She<sup>22</sup> said that she has been trying to get an appointment with the GP for two months but they have said that he is on holiday and been busy. Each time she phones she was told he is on holiday, busy, no more appointments. Because she [daughter] has got a disability, the GP should see you and she told her husband to say 'my child has a disability and my social worker said that they should see me', and she got an appointment. So it shows it works. It was a week later but at least she got something. She said that she thinks it is the nurses in reception.

Interviewer: What makes you think this?

Quaniah: She says that she doesn't know why but they weren't giving her an appointment, and as soon as they mentioned about the social worker they gave her the appointment.

Interviewer: So how well do you think services such as the hospital, doctors care for Muslim patients?

Quaniah: They're alright, they don't really pay much attention. The GP is fine. The receptionists just do that. They put things off by saying things like we are too busy.

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<sup>22</sup> Quaniah's interview was performed with the use of an interpreter. As such, some sections of the interview transcript appears in the third person.

Interviewer: Do you see this as having anything to do with being Muslim?

Quaniah: No, no. They are just like that.

Quaniah's account was echoed by many of the respondents in the study, who complained about aspects of health or medical services, but did not attribute this to discrimination or racism. For example, Parvina who cares for her son with Down's syndrome argued that when accessing health services, religious affiliation was not an issue:

The GP is good [...] she<sup>23</sup> doesn't think that religion makes a difference. We're all made of the same soil [...] They do look after you.

Similarly, Leila, who cares for her husband with physical disabilities and her daughter with learning disabilities, argued that religion and ethnicity does not factor into experiences of health services:

They [health services] are fine. It [religion and ethnicity] has no negative effect. She<sup>24</sup> said that she doesn't know how it would link because if you go through the proper channels, religion wouldn't come into it.

Leila continued by describing her GP as 'an angel' for the service he provides for her family, including access to appointments for

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<sup>23</sup> Parvina's interview was carried out with the use of an interpreter. As such, certain passages of the interview are presented in the third person.

<sup>24</sup> Leila's interview was carried out with the use of an interpreter. As such, certain passages of the interview are presented in the third person.

consultations and travel to the hospital:

If she needs an appointment for her husband she always gets it because he is disabled. If the doctor thinks that he needs to go to the hospital they will get an ambulance for him. They are aware of her daughter and her needs and they are very understanding [...] She says her GP is like an angel.

When respondents mentioned religious or cultural aspects of their encounters with health and medical services, they generally praised the availability of choice provided. For example, Foziah cares for her mother who has suffered a stroke and now experiences physical disabilities and visual impairments. She expressed positive opinions of the local hospital that her mother has been admitted to on a number of occasions:

[T]hey are very helpful. Especially the way mum is you know, they do cater for her needs [...] They tried everything because mum's a very fussy eater, like I told you before, and they provided *Halal* meals, even though mum didn't eat they were still there.

Echoing these findings, Vydelingum (2000), in his phenomenological study of the 'lived experiences' of hospital care from the perspective of South Asian patients, found that the majority of comments expressed by his respondents 'centred on how grateful they had been for the care they received' (p.102). In addition to praising how responsive hospital

services were in an emergency, patients were 'impressed' by the introduction of an Asian menu and the ability to wear traditional dress if they wanted.

Where health and medical services were unable to cater for religious and cultural requirements, respondents reported feeling satisfied with making alternative arrangements. For example, Ahmed cares for his adult son with learning disabilities. Ahmed suffers with a number of health problems and was recently admitted into hospital for treatment. Before entering hospital he assumed that the *Halal* meals would be more expensive, so when he was offered *Halal* food he turned it down on the grounds that he could avoid the non-*Halal* aspects of a hospital meal.

They asked me when I was admitted into hospital if I want the *Halal* meat. I said I will start with this one [non-*Halal* meals] because I can eat the fish and other things you see.

Similarly, Eshmaal, who cares for her daughter with learning disabilities, argued that she was happy with the treatment she and her daughter have received from the hospital and from her GP. Although she does not believe that *Halal* food is available, she argues that as Muslims, they understand what foods to avoid:

We can understand what we have to eat and not. The GPs give healthy food, but it is not like it is *Halal* or nothing.

Eshmaal's and Ahmed's responses were echoed by other carers in the study, where knowledge of how to uphold Muslim religious practices such as consuming *Halal* food was deemed sufficient when accessing health services.

Existing literature tends to suggest that language barriers are a particularly salient factor in the experiences of some minority ethnic groups accessing health and medical services (Hasnain *et al.*, 2008; Katbamna *et al.*, 2004; Kokanovic *et al.*, 2006; Manthorpe *et al.*, 2009; Neufeld *et al.*, 2002). However, respondents in this study rarely reported language being a barrier to access, even though a significant proportion of the participants either spoke English as a second language, or did not speak English (this is discussed in more detail in section 3.6). For example, Nisha cares for her elderly father with physical disabilities. She described how she has been with the same doctor's surgery for twenty-three years, and although there is a language barrier whereby her daughter or another family member interprets the consultations, she is happy with the service:

I have been with doctors for twenty-three year and we have a language barrier but my daughter or my family interpret that. I am happy with the NHS there. We visit the doctor regularly and not had a problem. They even visit us at home.

Similarly, some studies have suggested that Muslim patients are often concerned about only receiving consultations and treatment from health

practitioners of the same sex, and the potential for hospital gowns to be too revealing (Hasnain *et al.*, 2008). These concerns were not voiced by respondents in this research, which becomes of particular interest within the following section, where mixing sexes (*purdah*) at social services was considered particularly problematic for carers of females with learning disabilities.

In response to the positive perceptions of health and medical services, most carers in the study did not consider that any improvements needed to be made to the services they accessed for medical treatment and were only concerned that their level of support continued. For example, Quaniah, who cares for her daughter with restricted mobility in her arm argued: 'we have good help at the moment. I would like the government to carry on with what they are providing'. Similarly, Leila praised the level of government support for disabled people in Britain:

[H]ere [Britain], there is not anybody that is really poor because the government provides a lot of support for disabled people.

Phillips (2007) argues the general point that there is a widespread belief that medicine and health care are vital, whereas social care (discussed in the next section) is optional. In Chapter Four the findings suggest religious beliefs (or theodicies) pertaining to care were seen as a test from *Allah* to reap rewards and blessings in the afterlife, which gave added purpose to carers in providing the best form of care for their chronically ill or disabled family members. Furthermore, Hussein

Rassool (2000) points out that Muslims are encouraged to seek care and treatment in times of sickness.

These arguments may provide some context for understanding the positive responses presented by the carers pertaining to the receipt of health and medical services. Perhaps these findings also indicate that calls for increased awareness of diverse religious groups within much existing literature are gradually being addressed within health and medical services. These findings contrast with perceptions and experiences of social services, and are discussed in the section below.

### **5.3 SOCIAL SERVICES: GENDER, MANAGEMENT AND CONTROL**

The previous section explored how the respondents generally presented positive accounts of health and medical services. Negative encounters were perceived as being the disorganisation of the healthcare system rather than the result of religious insensitivities or racism. Furthermore, respondents reported that they were satisfied with making alternative arrangements if health facilities were unable to provide religiously or culturally appropriate services.

These findings starkly contrast with the respondents' accounts of accessing social services. Here, carers regularly complained that their religious and cultural needs were unmet, which resulted in general mistrust and negative perceptions of facilities such as special

educational needs schools, colleges, residential homes, play schemes and day care centres.

This section explores the respondents' accounts of social services, and is framed by the conceptual theme of purity and danger. To begin with, extracts from Hakim's interview, who cares for his son and daughter with learning disabilities, are used to provide a bridge between the health and social services sections. His accounts clearly demarcate the differing perceptions between the two. Whilst health services may be perceived as less problematic due to the carer feeling included in and involved with significant aspects of the health service experience, in contrast, access to some social services may require the carer to entrust the care of their relative to a facility, which was often perceived to be unable to cater for important religious and cultural requirements. In response to this, carers often spoke about how, in order to uphold religious and cultural values, they would manage, control and prevent access to some social services.

This form of negotiation was primarily dependent upon the gender of the cared for relative. Consequently two subsections separately explore how social services were experienced for carers of females, and then subsequently, carers of males.

As discussed in the previous section, Phillips (2007) argues that health and medical services are often perceived as 'vital', whereas social



services can be regarded as 'optional'. Moreover, differences between the types of care performed within each service also can differ substantially. Health care is often accessed in unpredictable times of acute illness, whereby decisions of treatment are dependent upon rational scientific methods of diagnosis and treatment (Phillips, 2007). Conversely, social care is regularly accessed as a means of supporting individuals with chronic conditions. In this way, social care may be performed indefinitely and on a regular basis. Phillips (2007) argues that in contrast with health care, social care is emotionally and intuitively performed, sometimes devaluing its importance for potential service users. These arguments were reflected in the accounts respondents presented pertaining to perceptions and experiences of social services.

As previously stated, the extracts from Hakim's interview, presented below, provide a salient example of how the differences in health and social services may have affected how they were subsequently experienced and perceived by respondents in this study. Hakim cares for his adult son and daughter with learning disabilities. Like many carers of males with disabilities in the study, Hakim was particularly concerned about his son consuming only *Halal* food (this is discussed in more detail in section 5.3.2 below). Hakim described how his son was afflicted with a serious bladder infection, which resulted in him being hospitalised for twelve days. In the quote below, Hakim describes how he was able to discuss with health professionals the treatment of his son. Furthermore, he was able to visit every day and provide his son all

his meals.

After about five or six hours they called him [son] in and put in a tube and got out about three bottles of urine. And after that I asked if it was OK and he [doctor] said 'no, I want to get a surgeon, we can't let him out'. He was in hospital for twelve days [...] Every morning I went down at nine am with food and gave him breakfast, lunch, dinner, tea. Every day.

As Hakim's account illustrates the extent to which he could be included in, and have control of, certain aspects of the hospital stay, these findings echo Judith Okely's (1983) ethnographic observations of the Traveller-Gypsies. Although Gypsies perceived health services such as hospitals as *mochadi*, or polluted, as they represented the *Gorgio* value system, they were often seen to be necessary for curing diseases and ailments. Consequently, encounters with hospitals were often managed and controlled. Some Gypsies in her study refused all food served in hospital. Instead food was brought in by relatives who would often break hospital visiting hours to be at their bedside.

Although Hakim could exercise control over his son's food requirements when in hospital, he also presented an account of a negative experience with his son's food requirements whilst at a day care centre. He described how distressing it was to discover that the food at the centre was served on one table, making *Halal* indistinguishable from non-*Halal* food:

I went down there one day and asked for the manager and asked what he [son] was eating and he said 'I don't know'. I said 'you are the manager!' He said 'no, we put it all on the table with empty plates so they can choose what they want to eat'. There is pig, everything down there. Pork, gravy, everything and he was eating you know? From that day on my son didn't eat away from home.

In contrast with Hakim's positive experience at the hospital, an encounter with his son's day centre revealed how in his opinion staff did not take adequate measures to ensure that he only consumed *Halal* food. In response to this, Hakim reported that he no longer allowed his son to eat food away from home.

The accounts presented by Hakim pertaining to experiences of health and social services were reminiscent of many of the carers in the study, who reported that the performance of care carried out at certain social care facilities were incongruous to the respondents religious and cultural requirements. Consequently, to uphold a sense of religious identity, carers were required to manage, control and prevent access to, and experiences of some social care facilities. Okely (1983) also observed how Gypsy parents controlled and prevented incursions into the mainstream *Gorgio* culture. Here, parents regularly refused access to education and schools, fearful that they would 'pollute' children with *Gorgio* values. Similarly, Gypsy children's contact with *Gorgio*'s was heavily monitored and overseen by parents at all times.

It may be argued that these forms of monitoring, management and control are a form of 'love labour', where carers attempt to protect and provide the best form of care for their relatives. As discussed in Chapter Two, Lynch (2007) employs the concept of 'love labour' to define a distinct form of care that is 'non-commodifiable' in that it cannot be supplied on a paid basis. Lynch describes love labour as work that:

[I]s undertaken thorough affection, commitment, attentiveness and the material investment of time, energy and resources. It is visible in its purest form in relations of obligation that are inherited or derived from the deep dependencies that are integral to our existence as relational beings (p. 557).

She continues by arguing that:

It also refers to the very real activities of 'looking out for', and 'looking after' the other, including the management of the tensions and conflict which are an integral part of love labour relations. For the person who has the primary responsibility for the care of vulnerable others in particular, it involves drawing up the care map for the other. It involves carrying the care map in one's mind at all times, and overseeing its implementation in terms of scope and quality throughout the care journey (p. 559).

Lynch's (2007) concepts of 'love labour' are reminiscent of the accounts presented by the carers in this study. As Chapter Four demonstrated,

religious beliefs were a salient factor in both the perceptions and performances of care. Moreover, mediating the performance of care through a religious lens was of particular importance to some respondents. As such, upholding a sense of Muslim religious identity was often a regular addition to a participant's 'care map'. Lynch's (2007) arguments provide an illuminating perspective on how some social services were unable to carry out some of the religious dimensions of the 'care map', which often required the respondent to 'redraw' aspects of the map to control and manage access to these facilities. This process of 'looking out for', and 'looking after' those being cared for heavily depended on the gender of the individual being cared for. As such, the following two sub-sections will discuss these themes separately.

### **5.3.1 CONTROLLING AND MANAGING THE DISABLED MUSLIM FEMALE: *IZZAT*, *PURDAH* AND *MADRASSAS***

Many respondents argued that caring for a female with learning disabilities required an extra duty of care, over and above caring for a male with learning disabilities, due to the perceived need to protect their moral Muslim reputations (*izzat*). This formed a salient theme within the data and is the focus of discussion in this subsection.

When speaking about females with learning disabilities, respondents regularly spoke about how the potential dangers and 'risks' of social services threatened their cared for relative's purity, 'cleanliness', and

perceived vulnerability. Consequently, respondents often reported that they prevented female relatives with learning disabilities from accessing any form of social service. In this way, Mary Douglas's (1966) and Judith Okely's (1982) theories of purity and pollution are particularly relevant and are drawn upon throughout the subsection to contextualise the experiences of the carers.

Twenty-two out of the twenty-eight carers in the study cared for a child with a learning disability, and of those respondents, eleven cared for a daughter. However, some respondents cared for more than one person and subsequently cared for a girl and a boy (see section 4.2 for the biographical data of respondents). No respondents cared for a parent with a learning disability, therefore, conclusions drawn within this subsection apply specifically to the daughters of the carers in the study.

As articulated in Chapter Three, at the beginning of each interview, respondents were asked to describe a typical day caring for their chronically ill or disabled relative (see Appendix 07 for a copy of the interview guide). Responses to this question often elicited interesting data about the participants' perceptions of caring for a family member. For example, Amina cares for her son with learning disabilities. She argued that as a Muslim caring was hard, however, to care for a girl would be 'a bit harder'.

It is hard work [...] You can't leave them with anyone because you are

the mum. We are Muslim and it's hard, we have a boy and that is all right but it is a bit harder to leave the girls.

Later in the interview Amina was asked to expand on why she thought caring for a girl is harder than to care for a boy. In response, she presented an account of a Muslim girl with learning disabilities that had encountered a negative experience in a taxi with a male service user:

[T]here was a boy and girl and they were going together and *I won't mention the name* but this happened in the taxi or whatever. But [now] she is refusing to go to college and she doesn't want to go *because he can speak a little bit but she can't speak at all*. She doesn't want to go and they don't know what happened to her, it was something to do with her vest and she can't say, she just kept pointing to her vest [...] *it was all very embarrassing* [emphasis added].

The two extracts of Amina's interview presented above echoed sentiments presented by many carers in the study. Namely, that females with learning disabilities are particularly vulnerable, they are more vulnerable than males with learning disabilities, and that caring for a female with a learning disability requires an extra responsibility of care to protect them from their vulnerability. The extracts above also allude to the potential consequences of failing to protect females with learning disabilities from the potential threats brought about by being particularly vulnerable. When Amina tells the story, she omits the name of the girl, implying that to reveal the girl's identity would compromise her

reputation or cause embarrassment. This is further reinforced by how Amina describes that the girl is now refusing to attend college *because* the boy can speak, thus implying that the potential for the boy in the story to divulge the details about the incident would be somehow undesirable. Consequently, Amina's account seems to focus on the potential for the incident to have challenged the reputation of the girl, arguing that 'it was all very embarrassing', echoing notions of family honour and *izzat*. This is explored in more detail below.

Much existing literature discusses the moral reputation of Muslim women and the impact this has on family honour (*izzat*) (Ansari, 2004; Brown, 2006; Cooke, 2007; 2008; Ramji, 2007). Hussain (2005) argues that preserving family honour and self respect (*izzat*) within South Asian communities is often regarded as being the sole responsibility of women. She also describes how *izzat* within contemporary British society faces a number of threats. As a secular British upbringing encourages notions of independence and choice for women, 'the notion of filial duty is difficult to shed without incurring feelings of vulnerability and guilt' (p. 526). Similarly, Cooke (2007) argues that gender and religion are so entwined that they have become one. She combines 'Muslim and 'woman' into one word: 'Muslimwoman' to describe a singular identity. She attributes this in part by growing global Islamophobia, where the 'Muslimwoman', veiled or unveiled, signifies a boundary between the 'inside' and the 'outside'. In this way, the 'Muslimwoman' requires protection from the potential of being polluted



by the outside in order to keep the inside pure. Cooke (2007) argues:

Cosmopolitanism is at once unifying and diverse because the more people identify with and connect to each other the more will their identities be hybrid and split among the multiple groups in which they act and want to belong. Those threatened by such hybridity in Muslim women may try to cage in the proliferating identities [...] The Muslimwoman, veiled or unveiled, has become the cultural standard for the Umma, or global Muslim society [...] In such a moral economy, women define the border between the pure and the polluted. The logic of the argument is that women are the potentially *outside* that insiders must keep pure or purify in order to save the purity of the *inside*. To uphold this moral regime, insiders must cooperate in maintaining and monitoring Muslimwoman appearance and behaviour [original emphasis] (p. 141).

Cooke's ideas about the 'purity' of the 'Muslimwoman' were echoed in the findings of this study and were introduced in Chapter Four. Here, carers regarded daughters and sons with learning disabilities as being physical gifts from *Allah* to test their patience, endurance and trust in *Allah's* divine plan. As such, respondents often referred to those they cared for as being angels, divine and pure. Consequently, it seems that to be female and to be disabled combines two identities that are regarded as being spiritually pure and in need of monitoring and protecting in order to uphold the sacred nature and purity of these identities. As such, the extent to which these identities need monitoring and protecting increases when they are combined. Thus, carers of

daughters with learning disabilities have an extra duty of care, which is based upon the perceived need to protect the moral identities (*izzat*) of their daughters. This may explain why so many respondents chose not to allow their daughters with learning disabilities to attend any social services.

Ghaada cares for her daughter with learning disabilities and also cared for her son with learning disabilities and challenging behaviour before he moved into a care home. Her daughter used to attend a day centre. However, after forming a friendship with a male service user, in addition to men replacing a number of the female staff at the centre, Ghaada discontinued her daughter's attendance. Her concern centred around the perception that due to her daughter's learning disabilities, she would not be able to behave appropriately when interacting with other male service users:

[S]he used to always have this boy and he used to hug her and sometimes it was all right but I didn't accept that [...] *she doesn't understand anything and he doesn't understand anything* either and so the only thing is to separate them. Don't put her next to this boy who is going to hug her and hold her, it is just not appropriate for us [...] The main thing people are worried about is the girls, our Asian Muslim carers or even, I mean there are some English people who would prefer girls with girls rather than girls with boys because their girls don't understand anything [emphasis added].

Echoing the findings and arguments of Hussain (2005) and Cooke (2007), Ghaada went on to explain that she would rather her son attended social care than her daughter, due to the vulnerability of girls with disabilities. In the quote below, Ghaada describes what she perceives to be the potential risks associated with allowing females with learning disabilities to mix with men, which seems to centre around the risk of engaging in sexual activity, and having a child out of wedlock.

[I]f I had a choice to put my girl or my son [into a day care centre], I mean, although I wouldn't mind both to go, I'd rather my son than my daughter. Because they are vulnerable. You have to be very careful looking after them because anything could happen. It is not easy [...] I mean I know times are modern but for our girls [...] But we rather that they get married before they have anything to do with men. In our religion when she is sixteen, eighteen, if she wants a boyfriend then it is best if she marries the boy. You don't just go out with him and do whatever and have fun, or even have a child, which *for us is very, very embarrassing, it is not accepted in our religion*. So that is why with us you have to be very careful. So they don't leave home, they don't stay elsewhere [emphasis added].

To implement Cooke's (2007) concepts of the 'Muslimwoman' here, the above extracts from Ghaada's interview may be seen to be a concern that due to her learning disabilities, a Muslim girl may not fully embrace what is expected of her appearance and behaviour unless the 'insiders', or carers, co-operate in maintaining and monitoring these

characteristics. These concerns subsequently provide a justification for preventing daughters with learning disabilities from accessing social services. These arguments are further reinforced by the following extract from Ghaada's interview:

To us, they may be adults but their understanding will be like small children. Sometimes we have to talk to them as small children to make them really understand. In the other way they say that they are adults and they have their own right and we do accept that as well, you know, what they like, but *there are limits*, where we understand the *dangers* [my emphasis].

Ghaada's description of 'knowing the limits' and 'understanding the dangers' seem to indicate a symbolic boundary beyond which lies danger, or the potential to remove purity. This largely encompasses Cooke's (2007) perspectives on the insider/outsider boundaries that the 'Muslimwoman' represents.

These findings also echo a wider anthropological point. As discussed above, much anthropological literature has observed the ways in which the rules and boundaries of the human body are a metaphor for the rules and boundaries of the social group (Bowie, 2000). Douglas (1966) argues that:

Certain cultural themes are expressed by rites of bodily manipulation  
[...] The rituals enact the form of social relations and in giving these

relations visible expression they enable people to know their own society. The rituals work upon the body politic through the symbolic medium of the physical body (p. 128).

As such, rites of bodily manipulation can be seen as a visual expression of group solidarity; concerns about bodily boundaries may be regarded as concerns about social boundaries (Bowie, 2000). In this way Douglas attributes the extensive purity rites of the Israelites in the *Book of Leviticus* as being due to their history of being a hard-pressed minority. In this instance, all by-products of the human body were polluting (e.g. blood, pus, excreta, and semen). Douglas (1966: 121) argued that: 'The threatened boundaries of their body politic would be well mirrored in their care for the integrity, unity and purity of the physical body'. In this way, Douglas predicts that the more a social group is threatened, the more visible the rituals of bodily manipulation become.

Douglas's (1966) theories have been observed by a number of empirical researchers who have suggested that a minority group's ethnic and religious identity heightens as a form of "cultural defence" in a religiously and ethnically different society" (Yip, 2004: 338). Pollution beliefs about mainstream society were also observed in this study, and may be observed in Leila's arguments about the early onset of her daughter's periods. Leila cares for her husband with physical disabilities and her daughter with learning disabilities. She described her difficulties in discussing her daughter's periods with the male staff at the special

needs school her daughter attends, due to her religious beliefs that sexual health matters should be personal and not shared with others. She described that:

[H]er<sup>25</sup> daughter started her periods when she was eight and she feels that Islamically it is something that you do not share with anyone else. Even in the same house, you try not to let siblings know that you are on [menstruating] [...] It bothers her because the head teacher and the deputy are both male and they know and she says that it is weird that within the same household nobody knows and yet complete strangers know that she has got this problem.

Subsequently, Leila argued that the early onset of her daughter's periods is caused by the openness of sexual expression in mainstream secular British society. She compares Britain to Pakistan, her country of origin and explains that in Pakistan, love, affection and sex are concealed behind 'closed doors'. In contrast, Leila has little control over the openness about sexual matters in mainstream secular British society, which she believes has an impact on her daughter's physical development:

I think that it is because of the environment and what they teach in schools that kinds of triggers these emotions. Here it is totally different. If my husband and I show affection to each other or show love in verbal or physical terms it is normally done behind closed doors, away from

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<sup>25</sup> Leila's interview was carried out with the use of an interpreter. As such, some parts of the interview are in the third person.

children. But here it is quite open to show affection and it does have a knock on effect because I cannot control what my children see [...] In Pakistan if you are pregnant then you try to hide it, however, here a mum gets pregnant and the first thing that she does is tell her child that she is pregnant and that's how I got pregnant and that kind of thing. It's just the way the culture differs. You have no control over what your child learns.

By combining the anthropological perspectives of purity and pollution in Douglas (1966) and Okely's (1983) work, with Cooke's (2007; 2008) arguments about the upkeep of the pure 'Muslimwoman' identity, Leila's comments (above) may be understood as being an interpretation of the physical consequences of the blurred boundaries that have come to exist between her Muslim Pakistani identity and secular British society. In this way, Leila's response seems to echo the concerns of many of the carers in the study; that entering secular British society may threaten the sexual purity of the girls they care for.

The moral reputations of the daughters that were cared for seemed to be steeped in notions of family honour (*izzat*), whereby concerns centred around the potential for females with learning disabilities to be polluted or morally corrupted by mainstream secular values. In this way, Leila's perspectives echo Okely's (1983) observations pertaining to Gypsy interpretations of *Gorgio* life as dirty and immoral. Okely argues that:

The most frequent accusations made against Gorgios are that they

kidnap, murder or 'interfere' with children. Gypsy children are not specifically told about assault, but are terrorised by stories of Gorgio child-thieves - strange men with 'long beards and briefcases'. Thus Gypsy children are kept within Gypsy space, and they learn to associate Gorgios with terrifying, predatory instincts. For parents, the specifically sexual innocence and vulnerability of their children symbolises their children's total vulnerability to Gorgio violation and control from which they must be preserved (p.168).

Leila interprets her encounters with the staff at the special needs school as an indicator of the sexual openness of mainstream secular society that she feels necessary to enter to provide the best care for her daughter. In doing so, however, Leila has perceived a symbolic physical, spiritual, psychological and moral consequence on the body of her daughter.

These interpretations echo Douglas's ideas about body manipulation discussed above, whereby concerns about a society (its sexual permissiveness) is given visible expression through the symbolic use of the physical body. Consequently, respondents regularly argued that practising *purdah* (separating sexes) and a Muslim religious education (*Madrassa*) was of particular importance to females with learning disabilities. These factors are discussed separately below.

#### **5.3.1.1 The Importance of 'Purdah' for Carers of Females with Learning Disabilities**



Respondents caring for females with learning disabilities were generally concerned about the perceived risks associated with mixed sex social services. Due to these concerns, many carers had never accessed services that provided social activities for their daughters. Other carers had accessed these services in the past but had encountered a negative experience with a male service user and subsequently discontinued their attendance. Of these respondents, most spoke about the need to protect their daughters from the possible 'risks' or 'dangers' that may be associated with allowing their daughter to access mix-sex facilities.

At the time the study was conducted, the only activities that the cared for daughters of respondents were currently accessing were special educational needs schools. Additionally, Fuseelah's daughter who has mild learning disabilities was employed by the local council, which was achieved through her affiliation with Organisation C<sup>26</sup> (this is discussed in more detail in Chapter Six.) As such, most carers expressed strong opinions about the need for single sex activities for females with learning disabilities. Hakim's care arrangements further demonstrate this point. He cares for his adult son and daughter with learning and physical disabilities. His son attends a day centre five times a week from nine o'clock until three o'clock, however, his daughter stays at home. He said that he would only allow her to attend an all female service that would be facilitated by a woman. He argued that mixing

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<sup>26</sup> Details of Organisation C can be found in section 3.5.3.

sexes was inappropriate:

Interviewer: Why does your daughter stay at home?

Hakim: We asked but it is our culture you know, and I see the television, you know? We wanted a separate woman classroom, woman teacher [...] it is a cultural thing, my wife and I are not trusting, you know? We don't mix, you know? It is not right.

Hussain (2005) reported similar findings in her study of South Asian disabled women. She explained that many parents in the study were less concerned about disabled sons than disabled daughters. In this way, she reported that boys were often allowed more freedom to socialise, whereas girls were prevented from attending social activities. She argues that:

Perceived threats to young disabled women's moral identities were countered by resisting their incursions into the wider social world. The father of Rukhsana Javed (Muslim, single, 19) did not like his daughter [...] attending social clubs for other disabled people, explaining that: 'I don't want her to go along with [the idea] that girls should have male friends' (p.528).

Although Hakim had never allowed his daughter to attend a day centre, other carers had considerable experience of accessing day centres, play schemes and colleges but had discontinued their attendance due to negative experiences with male service users at the facility. For

example, Eshmaal cares for her daughter with learning disabilities. She describes the school she used to attend as:

Eshmaal: [...] very good because if there was a Hindu festival they would celebrate it and if it was Muslim Eid they would celebrate it. They try to understand the children and how they celebrate for each religion. They did a drama and we went and saw it [...] she was Mother Mary in the Christian play.

Interviewer: Were you proud of her?

Eshmaal: Yes.

When her daughter was too old to continue accessing this school, she attended college for three days a week and a play scheme during the summer holidays. Subsequently, Eshmaal also enquired about sending her daughter to a day centre for the remaining two days a week. When she returned after the first day, Eshmaal described that she was distressed and subsequently refused to attend any of the activities that she was currently accessing. She argued that:

Before she was good, she was going to college for one year when she was 19, and she was perfectly fine going three days a week. Afterward I thought that the other two days she was just sitting in the house so I might join her somewhere else and I talked to the social services and they found a day centre for her, but they didn't tell me where they were going to send her, what time they were going to send her, they just

phoned me and asked the questions. In the summer holidays she was doing the play scheme and she was fine, painting, playing. I don't know, the taxi came one day and said we have come to pick up [daughters name] and I didn't know where they were going to send her. Then I sent her on the first day and when she came back she was very upset that day, I don't know what went wrong and they sent her in a mixed group, you know, all the boys and girls and something happened and she was very upset for two days. Something scared her and she stopped going to college that week and then after that she stopped going anywhere. Not even getting out of the house.

Due to her daughter's learning disabilities, Eshmaal explained that she was unable to decipher many details of the incident that led her daughter to refuse to attend these services. She told Eshmaal that 'the man was pulling me', although she said little more. As such, Eshmaal speculated that a male service user at the centre may have tried to touch her, which she would have objected to due to her being taught by her family and her previous school that it was inappropriate on religious grounds. She described how:

[S]he told me that 'the man was pulling me', somebody might have touched her, you don't know. Somebody might of said to her come or hold her hand and she doesn't like that, [...] especially the man, she doesn't like it. [...] [B]efore, she was always giving hugs to everyone, when she was in school. I went to the school and told them to teach her to not give hugs to everyone, because I don't like it. Because you know *in Muslim, it is not good of the girl[s] especially [that] hugs everybody,*

*the opposite person, you don't know how they think. Your mind is clean,*  
but the opposite person is how they feel. After that she was taught not to hug everyone, just to shake hands [my emphasis].

Eshmaal's account, above, demonstrates how she has attempted to teach her daughter to understand Muslim norms concerning conduct and behaviour with men. She alludes to beliefs about family honour (*izzat*) by arguing that 'in Muslim, it is not good' when girls hug people of the opposite sex. The above account conforms to Cooke's (2007) theories of the Muslimwoman, whereby Eshmaal reinforces the sense of her daughter's mind being 'clean' and in need of protection from the 'opposite person' whose mind is potentially unclean or polluting. Consequently, Eshmaal's daughter is not currently in receipt of any services that provide social activities. She described how she is aware of a service that would send a formal carer to provide social activities for her daughter, however, she argued that they were not able to guarantee that the carer would be female, which, due to her religious beliefs would be unacceptable.

They pay me money to hire a person to take her out. If I go through the agencies they provide the person to take her out and sit with her but they say they have got a mixed on, the men and the ladies, and they do not promise me or give me the guarantee that I will get only the lady [...]  
Whoever she is; white, black, Asian, as long as she is a lady. Because if she goes to the toilet, she doesn't know how to wash herself so I don't like a man to take her anywhere. So that is against our religion.

Ghaada expressed similar opinions to Eshmaal. As described above, Ghaada discontinued her daughter's access to a day centre after many of the female staff were replaced by men, and a friendship developed between her daughter and a male service user. She argued that she could not accept male professionals caring for her daughter:

That is what all people [Muslim carers] would prefer. Women with women. I mean I wouldn't mind if it were women with my son but I wouldn't accept men with my daughter. But in fact my daughters always say 'we are there for you and for her' so instead of sending her anywhere we'll take her [to them].

Concerns about females with learning disabilities mixing with the opposite sex led many carers to describe the importance of providing Muslim religious education, which would assist in socialising their cared for relatives into the appropriate and expected norms of behaviour for Muslim women. This is discussed below.

#### ***5.3.1.2 Exploring the Importance of Muslim Religious Education for Carers of Females with Learning Disabilities***

Carers of females with learning disabilities regularly described the importance they placed on their daughters attending classes for Muslim children, where they would learn about Islam and the importance of upholding certain religious behaviours. These facilities were defined by the respondents as '*Madrassas*'. However, Mosques (who generally

provide this educational resource) were perceived to be ill equipped to cater for people with learning disabilities. These issues are explored here.

Like the parents in Hussain's (2005) study of South Asian women with disabilities some carers in this study were concerned about their cared for relatives attending services that provided social activities, as they may negatively influence and socialise family members to behave in ways that are considered incongruous with Muslim cultural and religious values. Vardah cares for two adult daughters with mild learning disabilities. She reflected on when her daughters attended a local special educational needs school and argued that due to fundamental differences in religious and cultural beliefs, the school would inadvertently teach her daughters behaviours that were unacceptable to her beliefs. She described how:

Vardah: [W]e have certain things like girls not mixing [...] in our culture and religion [...] but it's different from your way and we couldn't express that because there was no-one to speak to really [...] It's mixed feelings really because we learn them something and then in school they learn something else [...] Clashes isn't it really.

Interviewer: So what kind of clashes have you come across?

Vardah: Like religious things you know. Like we learn our girls that you can't mix with boys, it's not good to go out and all that, you know. And

they learn it different [at school]. For you I mean it's a different thing. It's OK for [you to be] going out after sixteen, mixing with men. And that's fine. But that's not our religion. Our religion doesn't allow that you see.

As such, Vardah argued that there was a need for religious education for Muslim children with learning disabilities:

I would have liked something in place for Muslim children. If there was something in place at school then they would have followed a little bit our thing [religion] as well. It's not just educationally, there's nothing in place for disabled children religiously. There is more now, but it is not that much. Now we have got the lady teachers. Before it was just the men but now we have the women it's better because they are more compassionate. You can go to them and tell them, look she has got a disability and they will be more compassionate.

Vardah's views echoed other carers in the study who argued that it was necessary to provide education about Islam to Muslim girls with learning disabilities. Whereas most children attend classes in the evening to educate young Muslims about the principles of Islam (*Madrassa*), some respondents argued that these resources are not provided for girls with learning disabilities. Safia cares for her daughter with learning disabilities. She described how due to her daughter's learning disabilities, she is excluded from attending the local Muslim school (*Madrassa*):

Every day, if you are Muslim, your children go to evening school and that is called a *Madrassa* and they go for two hours and they start when they



are about four or five, it depends. They go every day and they just learn our Arabic words and the prayers so they get stronger from a very young age. It's not hard for them to connect with God and I think that is very important in our religion. My children go, except for [daughter's name] and that is lacking. Yeah, it's lacking in our religion. They have got no schools, no *Madrassa* schools for special needs or very disabled child, not that I know of. So at the moment what we do with [daughter's name], when the brother and sister pray, they are learning their Arabic at home. Before they go off to Mosque, we sit with [daughter's name], sort of teach her the alphabet from the very beginning. She is very delayed actually, her age should be second or third book so she is just starting. Because her words were not coming we didn't push her, we just stayed with her. She takes a very good interest in the religion, she knows the *Ramadan*, the *Eid*, the Christmas and why dad goes to Mosque to pray and why mum is putting on the outfit to pray and why she washes herself before she prays. She knows all that, and she copies her brother and sister you know, it's just, they are delayed, in our aspect of religion.

Similarly, Fuseelah cares for her adult daughter with mild learning disabilities. She explained how being Muslim forms a large part of her daughter's identity. She described how frustrated her daughter would become at not being able to access Muslim education. Fuseelah enrolled her daughter at Muslim school (*Madrassa*), however, due to her specific learning needs the classes were unsuccessful. Fuseelah complained that:

There is nothing for people with learning disabilities to learn about our

religion. So this is worrying, [...] yeah, it is very disappointing for me that people with mild learning disabilities can't go and learn about their religion. When she was young she used to get really frustrated so I enrolled her in religious class but then because the tutor was not trained, she just made her sit in one corner and that's it. With her you need a lot of cajoling. It is not about caring, I know, and I know [that] people with higher needs wouldn't understand, but the people with mild learning disabilities would definitely benefit from religious education. Even the schools could do something at the schools because [daughter's name] used to learn a lot when she did religious education. We have been trying to tell the community this for years but unless you have been affected by this. It is just being set up for life you know what I mean?

It appeared that part of the importance of religious education for the respondents was to prevent their children from being negatively influenced by the values of mainstream secular society. Vardah, who cares for two adult daughters with mild learning disabilities, argued that if Muslim religious education had been available to her daughters when they were at school, then it may have been easier for them to uphold Muslim religious values, rather than adhere to the values of secular mainstream society. As such, the exclusion of children with learning disabilities from local Muslim schools (*Madrassa*) heightened the sense that girls with learning disabilities were vulnerable because they had not been socialised in a process that Fuseelah described (above) as 'being set up for life'.

### **5.3.1.3 Summary**

This subsection explored the importance that carers of daughters with learning disabilities placed on upholding the purity of the daughters they care for. Okely's (1983) analysis of pollution beliefs employed by the Gypsies in her study is reminiscent of beliefs employed by the carers in this research. Here, respondents often reported preventing their daughters with learning disabilities from accessing social services as a way of protecting them from the possible 'dangers' associated with entering the mainstream British society.

Unlike the Gypsies in Okely's study, the carers in this study did not specifically report being concerned about the dangerous nature of the non-Muslim. However, mainstream British culture often contradicted the carer's religious beliefs, which made access to certain social services problematic for respondents of daughters with learning disabilities. This, combined with perceived ideas about the fragility of the 'Muslimwoman' (Cooke, 2007) often led the carers in the study to reflect on the vulnerability of their daughters and reinforce traditional beliefs about separating sexes (*purdah*) and family honour and moral reputations (*izzat*). For the respondents who had accessed social services that provided social activities for their daughters in the past, quite often their religious and cultural perspectives about the importance of female only groups had been reinforced by negative experiences with other men at the service. Additionally, carers were concerned that access to these services would confuse their daughters into thinking that socialising with

men was appropriate. As such, some carers called for Muslim classes (*Madrassa*) to be provided for their daughters with learning disabilities, which many respondents perceived would assist in socialising them into the appropriate behaviours of Muslim culture. This service was perceived by these carers to be unavailable at the time the research was conducted.

Contrasting with the experiences of carers of females, carers of men reported controlling and managing access to social services rather than preventing access. This is discussed below.

### **5.3.2 CONTROLLING AND MANAGING ACCESS TO SOCIAL SERVICES FOR THE DISABLED MUSLIM MALE**

As the following subsection demonstrates, experiences of social services for carers of males with disabilities fundamentally differed from carers of females. Here, males with disabilities were not perceived as vulnerable to pollution in the same way as females, and the purity of the cared for male relative was not seen to be at risk by attending most forms of social activity outside the home. Instead, Muslim religious values could be upheld by controlling and managing aspects of social service facilities, rather than preventing, as was the case with most carers of females. These findings are consistent with both Cooke's (2007) and Hussain's (2005) arguments. Because it is Muslim women who are generally perceived to be the guardians of family honour (*izzat*), and demarcate the boundary between the pure and the polluted,

it is consistent that carers of males have less to fear from pollution by social services. These findings highlight the gendered differences between perceptions of caring for females and males when accessing social services. Nevertheless, respondents who cared for men also described how they attempted to control and manage the services they accessed to uphold religious and cultural identities and values. Carers of men were most concerned about those they care for being inappropriately washed (*istinja*), consuming non-*Halal* food and drinking alcohol.

Winter (2000: 20) describes the Muslim practice of *istinja*, as requiring 'the use of running water to wash the genitals and anus after urination and evacuation'. Tanweer cares for her husband in the advanced stages of Multiple Sclerosis. Describing herself as a devoted Muslim, Tanweer explained how she has accepted that as a consequence of her husband now being permanently bedridden, he would not be washed in the ritualistic manner according to the *Qur'an* by the formal carers and nurses that visit. However, she reflected on her objections to him not being ritualistically washed (*istinja*) according to Muslim practices when he used to attend a day centre. She stated that:

[W]hen we use a toilet we wash ourselves and as a Muslim, that is what we do. But in my husband's circumstances I know it is not always going to be met because of the carers coming in are not Muslim or not Asian and don't understand this, they're not going to know any different are they? So I have always understood that and I have always let that go.

But I must say that when he used to go to the day centre, I used to think that when they take him to the toilet, I don't want all urine drops all over his clothes and things like that because as a Muslim we can't be like that, we see that as unclean. And at that time he used to do his prayers so praying as well, like in the day centre [...] [So] it was quite a worry for me because when he came home I would make sure that I could clean him to the best way that I could, you know, to make sure he was clean.

In this way, although Tanweer was dissatisfied with how her husband was cleaned at the day centre, instead of removing him from the service, she would attempt to manage this by cleaning him on his return home.

Similarly, many of the carers in the study expressed a concern that the male they care for was either consuming non-*Halal* food at the service they were currently accessing, or they were disappointed that the option of *Halal* meals was unavailable. This issue caused a significant amount of suspicion and distrust about the services that were being accessed. For example, Shereen cares for her son with physical and learning disabilities. Her local day centre informed her that they did not provide *Halal* food. As such, Shereen requested that he be fed only vegetarian food. She became suspicious that her request was not being met after she discovered what she thought was a piece of meat stuck in his mouth. She explained:

Well once they gave him meat and it was stuck and they said that 'no, it

was not meat, it was something else, we know that we don't give him meat'. But now we know they don't serve *Halal* food [...] so we send food there. Sometimes we put it in his bag so they microwave it there but we don't trust it.

The above account demonstrated how Shereen has attempted to regain control over a situation that has compromised her and her son's Muslim religious identity, by sending *Halal* meals to the day centre. However, Shereen also described how she continues to believe that the day centre does not cater to her religious needs, as she further described how she thinks they do not feed her son the food she sends in. Similarly, Iqraam, who cares for three adult sons with learning disabilities described during his interview how he does not trust the day care centre his sons attend to provide them with *Halal* food. Consequently, he described how he would like one of the professionals at Organisation B<sup>27</sup> to visit the day care centre to ensure that this religious requirement is being fulfilled.

We eat *Halal* you know, if you ever go to an organisation or shop where it doesn't cater for *Halal*, we tend to eat stuff that is suitable for vegetarians so at least you know that it has got non-Meat. I'm assuming that all day centres have mixed meat and veg so mixed for someone with learning disabilities - it's not good [...] I would like for somebody to go check, a social worker would probably be able to do that because a) I don't know what time they have their lunch and b) if I

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<sup>27</sup> Details of Organisation B can be found in section 3.5.2

try to go in, I don't know if they will allow me to go inside as they are having their lunch. So it's a case of I wouldn't be able to do that on my own, I need somebody to do that for me.

Shereen and Iqraam both demonstrate how the carers in the study manage to continue their son's attendance at the services they access, whilst upholding their religious and cultural needs.

Consuming alcohol is generally forbidden within Islam (Koçturk, 2002) and many of the carers in the study reported that abstinence from alcohol formed a core aspect of their Muslim identity. As Shereen, who cares for her adult son with physical and learning disabilities described:

Interviewer: Can you tell me what it means to you and your family to be a Muslim?

Shereen: Muslims; we eat *Halal*, we don't eat this and that and we can't drink and we don't go in the pubs, we have to be very careful. With [son], they [day care centre] know they can't take him to the pubs and not where everybody is dancing. We can't go there. Sometimes, eh, it hasn't happened to [son] but I know some people go and they just [...] give alcohol. In one time they gave him [someone she knew] alcohol and he came home and it was very bad.

Some of the respondents who care for sons with learning disabilities presented accounts of their sons being offered alcohol or being taken to



a venue that serves alcohol. Ghaada cares for her daughter with learning disabilities and also cared for her son with learning disabilities and challenging behaviour who now resides in a care home. Ghaada described how the care home staff informed her that her son wanted to go to a pub. When she told them that he wasn't allowed because it contradicted her Muslim beliefs, they argued that it was her son's choice:

They wanted to send him to a pub as well; they reckon he wants to go to the pub. I said 'why does he want to go to a pub? He has never, ever been in a pub'. He says 'well it is his choice' and I say 'he doesn't understand, why would you want to go to the pub?' He says 'social' and I said 'no, he is Muslim, he is not going to the pub'.

Ghaada refused to let her son go to the pub because it challenged what she considered to be a core aspect of his identity as a Muslim, and thus a core aspect of the family's identity. Atkin *et al.* (2002) reported similar findings in their study of young South Asian deaf people and their families. Many of the families in their research were disapproving and suspicious of the 'deaf clubs' that their deaf family members attended. Many in the study regarded the clubs as an 'extension of white culture' and were concerned about:

[T]he young person becoming over-westernised [...] They also saw the use of alcohol in social activities at the Deaf club as culturally and religiously unacceptable (p.36).

This quote relates the findings in this research as being consistent to those found in existing literature regarding the potential presence of alcohol when accessing social services.

This subsection explored how carers of men perceived, experienced and negotiated access to social services for their cared for relatives. Unlike the carers of females, who were often prevented from attending mixed sex facilities, carers of men were more concerned with upholding Muslim religious practices whilst at the service, such as being appropriately washed after going to the toilet (*istinja*), consuming *Halal* food and abstaining from alcohol. Consequently, respondents caring for men reported the necessity to control and manage social services, rather than preventing access. In this way, measures were taken to ensure that certain religious practices were upheld whilst continuing to access services, such as ritualistically washing their family members on their return from a social service, sending *Halal* food to day care centres, bringing them home for meals, and preventing the services from taking relatives to places that serve alcohol. These findings echo Hussain's (2005) arguments, where the disabled South Asian women in her study reported that men had more freedom to access social activities than women.

## **5.4 CONCLUSION**

This chapter explored how perceptions of and negotiations with state

services were fundamentally dependent upon the type of service being accessed, and the gender of the cared for relative. Health and medical services were generally positively perceived. Respondents reported being satisfied with making alternative arrangements if such facilities were unable to cater for their religious and cultural requirements. Further examination of these findings revealed that experiences of health services were often sporadic, and largely allowed respondents to control and oversee much of the encounter.

Perceptions, experiences and negotiations with social services fundamentally differed. Here, the findings reveal a marked contrast between respondents' attitudes towards female versus male relatives. Carers were primarily concerned for the moral reputations of females with learning disabilities. As such, accessing mixed gender services was often rejected as 'dangerous'. Carers regularly referred to their daughters as 'clean' and 'pure', strongly echoing Douglas's (1966) and Okley's (1983) arguments of how minority groups attempt to retain a sense of ethnic difference. In this way, participants expressed concerns that contact with men could corrupt or pollute their cared for female relatives. The findings also echoed Cooke's (2007) conceptualisations of the 'Muslimwoman', whereby the carers seemed to be fulfilling an extra caring role by observing, managing and controlling their daughters' entry into mainstream secular society, and therefore protecting their vulnerability.

Consistent with Cooke's (2007) and Hussain's (2005) assertions pertaining to women as the guardians of Muslim family honour (*izzat*), access to services for men with disabilities was more accepted by the carers in the study. The main focuses of concern here were the practical aspects of religious observance and upholding a sense of religious identity, rather than mixing genders, which seemed to solely concern females with disabilities. Carers spoke about the need to control certain aspects of how care was delivered in these services, such as performing religiously appropriate methods of cleaning after visiting a day care centre (*istinja*), ensuring that only *Halal* food is consumed by either sending food to a day centre, or bringing the cared for relative home for meals, and observing religious restrictions such as drinking alcohol.

These findings reveal the ways in which the Muslim family carers retained and upheld Muslim religious identities whilst accessing services, which often undermined and challenged core religious and cultural practices and beliefs. The ensuing chapter focuses on how the respondents in the study received support for their caring role.

## **CHAPTER SIX**

# **MUSLIM FAMILY CARERS AND SOCIAL CAPITAL: EXPLORING FORMAL AND INFORMAL SUPPORT NETWORKS**

### **6.1 INTRODUCTION**

As discussed in Chapter Two, the concept of social capital has provided an important framework for understanding Britain's increasingly diverse networks, ties, kinship groups and families (Field, 2003; Fine, 2010; Halpern, 2005). Findings in the data for this research indicated that the role of the family formed a significant theme. As such, the concept of social capital is specifically applied to this chapter as a way of exploring how, for the respondents in their caring roles, the family was a source of support but also, due to obligations and expectations, sometimes prevented access to receiving support from outside the family network.

Furthermore, an analysis of the four Muslim carer support groups, (see section 3.5 for a description of each organisation) accessed initially for sampling purposes, reveals the important supportive role that these organisations seemed to provide for many of the respondents in the study. The professionals interviewed for this research often argued that their occupational role served to 'bridge the gap' between the Muslim family carers, and access to support outside of the family.

As such, this chapter argues that Muslim family carers are not a homogenous group and their experiences of support are based upon a range of factors that include obligations, expectations, duties and the positioning of each social actor within the family structure. Accordingly, this chapter is loosely divided into two sections summarised below.

Initially, I explore how the respondents in the study explained how the performance of care is negotiated and allocated within the family. This analysis reveals a fundamentally gendered division of care. A further division of care labour between women suggests a possible 'hierarchy of caregiving' obligations and expectations within the family. In the following subsection I explore how the family supplied an important source of support for many of the respondents in the study. The final analysis in relation to the family explores how certain religious beliefs and cultural values about the nature of performing care sometimes restricted a respondent's ability to access support from outside of the family. Here, Putnam's (2000) contribution to the distinction between 'bonding' and 'bridging' social capital is implemented as a means of understanding how support from outside the family was experienced by the respondents in the study (see section 2.4.1 for a definition of these terms).

The second theme presented in this chapter pertains to the role of four Muslim carer support organisations that were initially accessed as a means of sampling Muslim carers. However, the process of data

collection revealed the interesting and important role that each of these organisations seemed to play in supporting many of the respondents within their caring circumstances. Consequently, this section explores how, by recognising the structural and cultural factors impacting on how Muslim family carers receive support, the organisations negotiated access to carers and supported them within the lived circumstances of their caring role. It also explores the relationship of the carers in the study to the carers' organisations, and the perceptions of the fifteen professionals also interviewed for this research, most of whom were either employed by, or connected in some way to the Muslim carers' organisation (see section 4.2 for the biographical data of carers and professionals interviewed for this research).

At the end of the chapter I present a conclusion that summarises the main points of the chapter and the wider implications of the findings.

Anthias's (2007) illuminating work on ethnic ties frames much of how social capital is conceptualised here. Although her focus is fundamentally different from my research in that she explores how ethnic ties can enhance or prohibit one's business opportunities, her arguments pertaining to social capital, especially for ethnic ties and networks, are particularly relevant here.

As articulated in Chapter Two, Anthias (2007) argues that the notion of social capital should be confined to resources that are mobilisable for

the pursuit of advantage or the mitigation of disadvantage (p. 788).

Social actors may have access to the same social networks, but will be positioned differently within them. In this way, membership to a group does not necessarily allow access to the same resources. Anthias (2007) argues that access to the resources of the group will be dependent upon differentiations between social actors, such as class, gender, authority, age, gender, as well as being a 'good' ethnic subject (p. 794). Moreover, the ability to mobilise the resources of the group will be dependent upon passing as an 'appropriate ethnic subject', which will vary according to the location of different social actors within the network.

Anthias's (2007) assertions that access to the resources of the group will be dependent upon the different valuations of each social actor, pushes the boundary of previous conceptualisations that she argues have risked essentialising or homogenising the experiences within and between social networks. As such, these arguments are deemed to be particularly important for exploring how the respondents in my study perceived, received and negotiated support for their caring role. Moreover, how their position within the networks to which they belonged both enabled and constrained access to further support networks.

As discussed in Chapter Three, interpreters were used for some of the interviews with Muslim family carers. However, if respondents understood the question, they would often directly respond. As such,



some passages of interviews carried out with interpreters are presented in the third person, and some in the first person. When a quote is presented in the third person, a footnote is added to provide clarification.

## **6.2 SOCIAL CAPITAL AND THE FAMILY: GENDER, SUPPORT, OBLIGATIONS AND EXPECTATIONS**

The concept of social capital was introduced in Chapter Two, and is generally defined in the literature as ‘the ability of actors to secure benefits by virtue of membership in social networks or other social structures’ (Portes, 1998: 6). The fundamental principle that ‘relationships matter’ (Field, 2003: 1) has led to many researchers analysing the ways in which membership to certain groups can be supportive, helpful and even emancipatory, whilst at the same time be the source of conflict, expectation, obligation and guilt (Goulbourne *et al.*, 2010; Goulbourne and Solomos, 2003; Smart, 2005; Zontini, 2006; 2010).

The above perspectives push the boundary of how informal networks and ties such as families and kinship groups have been previously perceived and discussed within social capital debates. For example, Coleman (1998) regarded the family unit as being of central importance to the educational attainment of children and their subsequent possession of social capital. Furthermore, Putnam (2000) regarded the breakdown of the traditional nuclear family as contributing to what he

perceived to be the decline of social capital in modern America. These contributions have been criticised for presenting an idealised, 'rosy' (Leonard, 2004), or homogenised view of belonging to families and kinship groups, which ignores or 'glosses over' the diversity of experience within groups, especially for women (for a more detailed discussion of these criticisms see Edwards, 2004; Molyneux, 2002). As such, this section specifically explores how the respondents in the study negotiated the allocation of care within the family. In particular, it explores the hierarchical nature of care within the family, the family as a source of significant support, and the restrictive nature of family networks and kinship ties.

### **6.2.1 EXPLORING HIERARCHICAL CARE RELATIONS WITHIN THE FAMILY**

Finch and Mason (1993) in their classic work on the family, argue that there is no simple way of explaining the relationship between gender and the negotiation of family responsibilities, however, they argue that a relationship does exist. Furthermore, they observe an additional relationship between genealogy and the ability to be excused from family responsibilities. As such, they argue that it is more helpful to understand how 'commitments and reputations developed over time, and how women and men, or different categories of kin, are likely to be differentially positioned within this process' (p. 125).

In keeping with Finch and Mason's arguments, this subsection examines how the data in this research suggested that different family members seemed to be positioned differently within the family, constructing what appeared to be a 'hierarchy of caregiving'<sup>28</sup>. Primarily, men seemed to be at the top of this hierarchy, occupying an advantaged social position within the family (Lin, 2000), where they are able to mobilise the most support resources from female relatives. These findings are consistent with existing literature that suggests that women undertake more care than men (Arber and Ginn, 1999; Dalley, 1996; Finch and Mason, 1993; 1999; Lewis and Meredith, 1988; McKie *et al.*, 2004; Oakley, 1974; Sullivan, 2000). A further interesting addition to this hierarchy also seemed to emerge from the data, which suggested an unequal division of labour between women, especially in elder care and in providing support for a primary carer within the family. Here, women married into the family (i.e. daughters-in-law; sisters-in-law) seemed to be regularly cited as providing significant amounts of hands on support and care for the respondents in the study, and for their chronically ill or disabled relatives. These findings are explored in more detail below.

All participants were asked who within the family provided care for their chronically ill or disabled relatives. Responses to this question were regularly accompanied by gendered beliefs about how responsibilities

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<sup>28</sup> This concept is borrowed and adapted from Cotterill's (1994) 'hierarchy of obligations', which is used (among other conceptual frameworks) to explore the mother-in-law, daughter-in-law relationship for a sample of white women in England. The hierarchical nature of care has also been acknowledged by other researchers such as Lewis and Meredith (1988), Punch (2001) and Silva (2005).

of care should be allocated and performed. When Chanda was asked about who within the family supported her in caring for her adult son with learning disabilities, she replied 'we women provide the care, Asian women is a bit different, our culture is a bit different'. These views were prevalent within the data, where gendered perceptions of care were often accompanied by religious beliefs and cultural values (also see Dwyer, 2000). Eshmaal provides an interesting example of how gendered and religious identities were often combined.

In our religion, even my husband will never take [daughter's name] to the toilet, even since she was small. But nowadays they get married and the husband- they both do the same job! The husband looks after the children and they change the nappies and everything but in my days, in Muslim, even now, as like an older person, *we don't allow the men even to change the nappies. It is very against our religion especially for the daughters, and my point of view that it is not good that the father does that [...]* There is social workers that can help with these issues but still they are not getting the help. If you are a mother then you can do it. I have got a son and I can do everything for my son, but father doing it for the daughter, it is not good. That makes me very unhappy and sometimes I think about that [my emphasis] (Eshmaal cares for her daughter with learning disabilities).

Eshmaal's perspectives of how she disagrees with the prospect of conjugal roles within modern Muslim households on religious grounds

was also echoed by Leila, who describes caring as her religious duty as a wife:

In the *Qur'an* it states what the wife's rights are and the husbands rights are and within the rights there are certain things that I need to fulfil to become a good wife. [...] Therefore, when I am doing these caring duties, I am basically fulfilling the religious aspect of it (Leila cares for her husband with physical disabilities and her daughter with learning disabilities).

Chanda, Eshmaal and Leila's gendered views about the allocation of care were echoed by many of the carers in the study and presented a dominant theme within the data. Furthermore, the addition of religious beliefs and cultural values seemed to provide a legitimate argument to these gendered perceptions. The reinforcement of gendered divisions of labour through the support of religious beliefs was also observed by Molyneux (2002) in her examination of gender and social capital in Latin America. Here, cultural norms under Catholicism strongly reinforced gendered divisions of labour and motherhood as embedded within the female identity. Consequently, it may be argued that religion may play an important role in shaping the gendered expectations of its adherents (also see Ramji, 2007; Williams and Vashi, 2007).

Gendered perceptions of how care should be allocated and undertaken within the family were supported by accounts of who within the family performed the majority of care responsibilities. As such, participants

described that care was both carried out by women and supported by women. The respondents in the study were asked to describe a typical day caring for their chronically ill or disabled family member/s. This question was designed to elicit how duties of care were negotiated and performed on a day-to-day basis. Subsequent questions were then asked about the types of support they received from family members. Responses to these questions revealed that the female participants in the study reported undertaking the majority of daily caring tasks. Conversely, the male participants in the study described how significant amounts of the day-to-day care work, was carried out by female members of the family. Furthermore, respondents who reported carrying out the majority of care responsibilities generally also reported receiving support from female relatives. In this way, men seemed to be markedly absent from the respondents' accounts of who within the family provided care.

Leila cares for her husband with physical disabilities and her daughter with learning disabilities. Leila's response (presented below) to the question 'tell me about a typical day caring for your husband and daughter', is typical of the responses given by the female carers in the study. Here, she speaks personally about the caring routines she undertakes:

Leila: She gets up at six. First she does her bit and then she wakes up her daughter. Her daughter is ten and when she wakes up she needs supervision and guidance with every job like going to the toilet and

brushing her teeth. She doesn't know about personal hygiene. Then she makes breakfast for all three of them and makes lunch for [daughter's name]. If there is any time left she will tidy up the kitchen. [Daughter's name] has a taxi and Leila will escort her to the taxi. She has to be at work at midday so between nine and eleven so she has to prepare the tea and arrange the appointments for her husband before she goes. She returns at seven. They all sit together and have tea and watch TV and then go to bed at half nine. On the days she doesn't work she does all the other jobs.

Interviewer: Does anyone else help you caring?

Leila: No.

Similarly to Leila, most of the female carers in the study reported that they carried out the majority of care for their chronically ill or disabled relative/s. These responses differed from how the male carers in the study described the day-to-day routines of care, where it was generally reported that a female relative undertook the majority of these responsibilities. Furthermore, they tended to speak about contributions that could be perceived to be somewhat 'male oriented'. These responses are examined in more detail below. However, interpretations of this data are somewhat tentative as only three male carers were accessed for interview for this research.

Iqraam cares for three adult sons with learning disabilities. His description of a typical day suggested that his daughter-in-law

supported many aspects of the caring responsibilities such as cooking and cleaning:

Iqraam: After prayer he gets his kids to have breakfast and then he gets them off to school. They go to the centres, not the schools. They all go to centres. He does have a daughter-in-law, who lives, like, a few doors away. So that daughter-in-law will come and help with the house, with cooking, cleaning and things like that. The daughter-in-law takes care of things. He just has to make sure that he puts breakfast and things like that on the table for them.

Interviewer: And does your daughter-in-law come and help every day?

Iqraam: Yes every day. And then they start coming home from about quarter past three to four thirty, they all come at different times and then obviously, he'll give them tea and things. It's already cooked and stuff by the daughter-in-law and he gives them the food.

Similarly, Hakim identified himself as a 'sole carer', however, his description of caring for his son and daughter with learning disabilities implied that his wife carried out the majority of care labour:

Early morning my wife gets up and gets breakfast, dresses and washes them. We did an extension about eight years ago that I paid for entirely myself and we make this room that we put in a sofa so that my missus can see them from the kitchen [...] About 5 o'clock she gives them fruit or cake or biscuit and then about half past eight we



have dinner.

What is also interesting about Hakim's quote is how he separates the contributions of himself and his wife. Here, his wife is attributed with performing the majority of the domestic tasks such as feeding, dressing and washing. In contrast, he describes how he paid for an extension to the house 'entirely myself', implying that the financial aspects of care are controlled by him. These findings were also echoed in Ahmed's interview. He cares for his adult son with learning disabilities. Although he described his family as supportive of his son's domestic needs, he mirrored the gendered attitudes in Hakim's interview when he joked: 'Fifty years of work, now I can relax, she looks after me!' [points to wife and laughs].

The gendered division of paid and unpaid labour within the family is central to debates around care. Most feminists agree that the classic 'male breadwinner' role has somewhat declined as women have increased their participation in paid employment, however, patterns of male contributions to unpaid domestic care work is complex (Lewis, 2001; Pascall and Lewis, 2004). In the 1995 General Household Survey, a surprisingly high number of men identified themselves as carers, challenging some existing assertions about the gendered domestic division of labour among carers. However, a thorough examination of the data revealed that male carers tended to care for less hours than women, and excluded carrying out intimate caring tasks (see Dalley, 1996).

These findings are also supported by a wealth of existing research, which argues that gendered attitudes towards the domestic division of labour within the home is often negotiated through socialised beliefs about gender roles. For instance, Ungerson (1987) in her classic work on sex, gender and informal care argues that not only are women more likely to perform larger amounts of care and undertake more intimate tasks than men, but that there are marked differences in how women and men speak about care. In her study, the male respondents drew heavily on their professional experiences of paid employment to provide context and method for their caring roles. For example, she was particularly surprised by the intensity with which the male carers in her study 'translated concepts such as efficiency and productivity from the business world into the domestic domain' (p. 104). Some researchers have further contributed to these debates by arguing that the gendered division of labour is additionally complicated for some migrants to Britain. Based on findings in their research, McIlwaine *et al* (2006) argue that migrant identities in low paid employment is both gendered and rooted within ethnic and national differences. Here, men in particular formulate new gendered identities, which seek to validate their masculinity and explain their employment in low-paid and often feminised forms of labour.

These debates provide a possible context for some of the responses of the male carers in this research. As care work is often categorised as feminine labour, they may perceive that their contribution to the care of

a family member should fall within tasks that have classically been considered to be male oriented. This may include providing for the family financially, or overseeing the monetary aspects of care. Additionally, responses pertaining to the financial aspects of care may also indicate an attempt by the male carers in the study to legitimate a sense of masculinity whilst occupying a classically feminised identity of being a carer.

Returning to Finch and Mason's (1993) arguments pertaining to the need to explore the position of social actors within the family to understand how family responsibilities are negotiated, the findings in this research suggested that the male respondents seemed to occupy an advantaged social position, with which to mobilise the support resources of female family members. These circumstances seemed to be reinforced by gendered religious beliefs and cultural values, which legitimised care works as ultimately a feminine undertaking. Consequently, it may be argued that men inhabit the top of a care hierarchy within the family, with the greatest ability to mobilise capital because of their gender.

A further division of care labour seemed to exist between women, where women married into the family (i.e. daughters-in-law; sisters-in-law) were regularly cited as undertaking a substantial amount of care for a chronically ill or disabled relative. Henz (2009) provides an illuminating account of how informal care is provided for parents-in-law.

Undertaking a descriptive and multivariate analysis on data generated by the British General Household Survey, her findings suggested that daughters-in-law were more likely to take on direct responsibilities for the care of a parent-in-law than a son-in-law. Similarly, Umberson and Slaten (2000) acknowledge the propensity for daughters-in-law to provide care for a parent-in-law. These findings have also been observed by Kim *et al.* (2003) in relation to Korean carers, however, this care relationship has received relatively little attention in relation to Muslim families. Dhami and Sheikh (2000) refer to the Muslim cultural practice of new brides moving into the home of their husband, and the possible 'teething problems' (p.45) associated with this process, however, the position of these women within the family in relation to the negotiation of domestic labour remains relatively under researched within existing literature.

Interestingly, very few carers interviewed for this research identified themselves as a daughter-in-law, sister-in-law, or mother-in-law, therefore, these findings were predominantly based on the accounts of respondents who cited themselves as being the main carer, but who received substantial support from a relative married into the family. Foziah, who volunteered to be interviewed on the grounds that she was the full-time carer of her elderly mother, demonstrates this negotiation of care labour. On arrival at the address I had been given to carry out Foziah's interview, it became clear that she did not provide the majority of care for her elderly mother. The address I had been provided with

was Foziah's brother's house, and the responsibility of care for her elderly mother lay primarily with her sister-in-law. Nevertheless, Foziah counted herself as a full-time carer, visiting the house daily to provide care for her mother and support for her sister-in-law. In the quote below, Foziah explains how the care for her elderly mother is allocated within her family:

Foziah: It is a lot for everybody, especially my sister-in-law who looks after her. In the night she gets up about three, four times [...]

Interviewer: When she gets up in the night does your sister-in-law have to get up with her?

Foziah: Yeah, yeah, they're in the same bedroom and she has to get up, sit her up and put her on the commode or you know, whatever she wants she'll do.

Interviewer: How often do you see your wider family?

Foziah: *I will come every day, my brothers visit her a couple of times a week.*

Interviewer: Do they help when they come over?

Foziah: If there is a need but the problem with my mum is, she doesn't like anyone to do anything for her except for this sister-in-law and her daughters – she is very used to them you know.

Interviewer: Yes. So it's your sister-in-law who is the main person –

Foziah: Yeah. The main person who does everything [...] I mean she's always lived with my mum and since mum's had the stroke 13 years ago she has looked after her.

Interviewer: How does caring make you both feel?

Foziah: It's a duty. I would say. It's a duty that we have to do. You know?

Sister-in-law: Same here [...]

Interviewer: What do you both do to relax?

Foziah: Relax! [Laughs] I mean eh what do you do? You can't do much can you? [...] My sister-in-law, she'll go back home to Pakistan for about three to four weeks, once a year or once two years *and I have to come and help*, daughters are very helpful, they'll help, but that's how it goes. [my emphasis] (Foziah cares for her elderly mother, who suffered a stroke over ten years ago, which left her with physical disabilities and visual impairments)

The above extract demonstrates how each family member contributed to the care of Foziah's elderly mother, but the extent of the contribution

vastly differed. Moreover, this differentiation seemed hierarchical, gendered and ultimately dependent upon the position of each social actor within the family network. In this way, Foziah's interview provides additional support for a proposed 'hierarchy of caregiving', where one's position within the family dictates the extent to which they are involved in the day-to-day care routines of their chronically ill or disabled relative/s. The account that Foziah provides may indicate that her brothers occupied the top of the hierarchy, who she explained visited 'a couple of times a week' and contributed very little to the practical performance of care duties. Further down this hierarchy was Foziah, who did not live with her mother, but who visited daily to contribute to the care work and support her sister-in-law. She also acted as a substitute carer when her sister-in-law was on holiday. At the base of the hierarchy was the 'sister-in-law', who was responsible for the greatest amount of care work. This included the longest hours (providing care throughout the day, and assisting her mother-in-law three or four times in the night) and the most intimate care tasks (I was shown that the sister-in-law shares a bed with her mother-in-law so that she can assist with toileting during the night).

Foziah's circumstances of how care was negotiated and allocated within the family were echoed by many of the carers in the study, who reported receiving substantial support from women married into the family. For example, Chanda described how her daughter-in-law carries out all the domestic labour within the house, including the cooking and

cleaning so that she is able to concentrate on providing care for her adult son with learning disabilities. Similarly, Parvina described how the only support she received for the care of her son with Down's syndrome was from her sister-in-law, who she explains 'is a bit scared because it has not been long that she has been here [in Britain] but she still tries to help in whatever way she can'.

In reference to existing literature on the family structure of 'in-laws', Cotterill's (1994) work on the mother and daughter-in-law relationship provides an interesting addition to knowledge on a topic that has been relatively undeveloped within sociological discourse (Turner *et al.*, 2006; Edwards, 1994). Using data drawn from in-depth interviews with mothers-in-law and daughters-in-law, Cotterill (1994) argues that these relationships are complex and highly variable. In this way, cultural and situational factors intersecting these relationships can shape how and if care is given and received by mothers and their daughters-in-law. Consequently, some woman may feel more obliged to give care to her parents than to parents-in-law. Furthermore, higher incidences of divorce, remarriage and geographical location may reduce the expectations imposed on a woman providing care for her parents-in-law. Cotterill's contribution shapes how the findings in this research may be interpreted. Muslim cultural practices observed by Dhami and Sheikh (2000), in which a bride moves in with her husband's family upon marriage, combined with the gendered perceptions of care espoused by many of the carers in the study, may render the daughter-in-law or



sister-in-law as the most obvious candidate for care responsibilities within the family, especially if daughters have been married into other households.

This subsection specifically focused on how the carers in the study negotiated the allocation of care responsibilities within the family. Through an examination of the data, it was suggested that a 'hierarchy of caregiving', often based on, or legitimised by gendered religious beliefs and cultural values, painted a fundamentally feminine picture of whom within the family carried out the majority of care. Furthermore, a possible addition to the hierarchy that existed between women was proposed. Here, women married into the family, such as a daughter-in-law or a sister-in-law were regularly cited as providing significant amounts of support for a respondent in their caring role. In this way, it was suggested that family structures resulting from Muslim cultural traditions of women marrying into the household of her husband, may situate the new bride as the obvious care provider within the family network.

These findings within the study remain somewhat undeveloped, principally due to the fact that very few respondents reported that they cared for an in-law. An interesting addition to knowledge would be to explore the perceptions and experiences of women married into the household of their husband, to further understand how the domestic division of labour is negotiated within some Muslim families.

Furthermore, existing literature pertaining to the role of 'in-laws' within research on the domestic division of labour appears to be rather undeveloped within sociological discourse (Edwards, 1994). This reveals an interesting and important gap in knowledge that is not always acknowledged within family studies. As such, these findings contribute to suggestions for further research made in Chapter Seven.

### **6.2.2 THE MUSLIM FAMILY AS A LOCUS OF SUPPORT FOR CARERS**

This subsection examines the supportive role of the family for many of the carers in the study. It explores how perceptions about the distinctive close-knit features of the typical Muslim family may serve to reinforce the existence of traditional family values, echoing the findings in Chapter Five. The argument that social capital is in decline as a result of increased global mobility is also challenged within this subsection. Here, it is argued that the respondents in the study who migrated from different parts of the world often created both new close family ties here in Britain, yet kept significant links with family left behind in their country of origin. Consequently, this subsection argues that the data suggested that family support could transcend national boundaries, and thus provides a range of practical and emotional tasks (Zontini, 2006). These arguments locate aspects of the research within a growing body of literature that challenges the perception that migration necessarily weakens social capital.

The perception that family structures are changing is popular within academic literature (Allan, 1999). Moreover, the transnational migration of individuals and families across national boundaries has resulted in increased variation in family and kinship relations (Allan, 1999). These changes have also been observed by social capital theorists, who have classically perceived such diversity in family structure as contributing to a decline in social capital; subsequently advocating policies to strengthen the traditional nuclear family (Coleman, 1988; Israel *et al.*, 2001). Putnam (2000: 390) argues that 'emigration devalues one's social capital, for most of one's social connections must be left behind'. These perspectives have been challenged, however, by a growing body of literature suggesting that in some transnational contexts, the family continues to 'perform numerous emotional and practical tasks for the individuals who form them' (Zontini, 2006: 341; also see Goulbourne *et al.*, 2010; Zontini, 2010). Consequently, researchers are increasingly challenging classical conceptions and definitions of the 'family'. For example, Finch (2007) argues that the 'family' does not necessarily equate to the social actors residing within a 'household', pointing to the diverse connectedness of kin across households (also see Baldwin and Carlisle, 1999). Similarly, Ansari (2004) argues that even though certain aspects of traditional Muslim families have broken down as a consequence of both the migration of certain family members, and the restrictive British immigration laws (also see Neufeld *et al.* 2002), the family has remained a focal point for the majority of Muslims:

Breakdown of extended families among Muslims from many parts of the world has occurred to a certain extent, partly as a result of the migration of individual family members and the enforcement of British immigration restrictions. However, recent evidence suggests that, while the organisation of joint and extended families has been much weakened because of housing difficulties and much greater mobility, the family has remained a focal point for the vast majority of Muslims, South Asian or otherwise, in Britain (p. 278).

These arguments were reflected in my research, where respondents regularly presented a connection between their Muslim identities and the perceived closeness of their family. For example, Omera compared the experiences of her elderly father-in-law (who has now died) with her perceptions of an 'Englishman' living next door. She described how the 'Englishman' rarely received any visitors but her father-in-law received many. This comparison was accompanied by a presentation of her Muslim religious identity, detailing how religious praise for the giving of care made her happy in her caring role:

I have a neighbour who is an Englishman who sits outside all day. He has had a hip replacement. He doesn't get any visitors. We always look at his life and we think what a boring life and how sad it is for nobody to visit you. When I was caring for my father I had visitors all day and all evening. To put this back to the religion, when you have visitors, they pray for you and the elderly, when they pray they will say 'God, because they are looking after me, please give them something in return'. If they pray for their happiness, even when they do

something so small they will say 'thank you so much, God will keep you happy'. I get so happy with them saying that, that you forget everything that you have done for them (Omera cared for her elderly father-in-law before he died).

Omera's response highlights an additional theme within the data. Here, respondents presented a comparison between the closeness of their own families with the perceived individualism of British society. This was also interestingly demonstrated by Hakim, who argued that he was proud of being Muslim, comparing his perceptions of (what I interpreted as being) low family communication in secular British families, with his own family who are in regular contact with each other.

Hakim: In Islam there is more care for disabled people as well.

Interviewer: How does that make you feel as a Muslim caring for somebody?

Hakim: These are the reasons I am proud of being Muslim. Your people [points to interviewer], how many times do they go and see their mother and father? Christmas day or birthday? Hey? My son comes back once a week, we give them a ring every day [and ask] 'are you alright, do you need anything?'

Omera's and Hakim's responses were echoed by other carers in the study and supports existing literature suggesting that the family continues to play a central role in the formation of a Muslim religious

identity (Dhami and Sheikh, 2000). Ansari (2004) argues that Muslim communities have attempted to resist the perceived dissolution of the family within secular British society:

Their perception of the changes in British society seems to have been that the family is in a process of decay and dissolution primarily due to the moral laxity brought about by secular developments and a materialistic outlook – a trend they have sought to resist through family cohesion (p. 278).

In this way, the findings here echo the arguments presented in Chapter Five, in which the data suggested that a sense of religious identity was upheld and maintained by resisting negative perceptions and stereotypes about secular British society.

The findings detailed above explore the perceptions that the respondents presented about the supportive nature of the family, however, participants also presented accounts of the practical ways that they were supported by the family networks to which they belonged. For example, Tanweer cares for her husband in the advanced stages of Multiple Sclerosis. She described how she is supported by both her daughter, and her family who live ‘just a few doors away’:

Tanweer: We have a daughter who is fifteen and obviously she is at school but when she is at home and her dad needs changing, if he has opened his bowels, if he has slipped down in the bed and needs putting up then she helps me with all that.

Interviewer: Do you have support from any other family members?

Tanweer: Yeah. Also I have family down the street, just a few doors away and if I need them, they are here for me.

Tanweer's description of the support she receives from her family is also echoed in Quaniah's account of the support she receives from her sisters-in-law. Quaniah cares for her daughter with restricted mobility in her arm. This disability causes her daughter severe pain and she requires assistance in the majority of her everyday tasks. Quaniah lives in an extended household, which includes her mother-in-law, father-in-law, her husband, his brothers and their wives. She described the help that she receives from her sisters-in-law, and how she misses this help when they are not available:

Sisters-in-law help sometimes, they make food and help her [daughter] get dressed, and other things like that. This is quite good. She [daughter] really makes me fed up and they help me cope. When I am on my own with her and they are not about, then that is hard.

Tanweer and Quaniah's accounts suggest that some of the carers in the study were able to mobilise the resources of the family into support that could successfully assist their caring role. In this way, these findings support arguments espoused by some social capital theorists that close family ties and networks increase social capital (e.g.

Coleman, 1988; Israel *et al.*, 2001; Putnam, 2000). However, close family ties were reported by most of the carers in the study, irrespective of whether the family was close in proximity to the respondent or in another country. For example, Amina cares for her son with learning disabilities. Her interview suggested that she was able to successfully mobilise the support resources of both her in-laws who live in India, and her biological family living in Britain.

Amina: I went to India to see my in-laws and he is a special boy, everybody looks after him – gives me a break.

Interviewer: So do you have a lot of support from your friends and family?

Amina: Yes, especially from my family. They live just close by.

Warda's interview produced similar findings. She described how she moved to Britain from Turkey to receive better healthcare for her son with learning disabilities. Consequently, she explained that she receives very little support for her caring role in this country, primarily because her family live in Turkey. However, she tries to visit regularly, where she reports receiving significant support from her family.

It is very nice to go home. I get a lot of support then [from family]. They think he is very special because he was the first grandson and he is loved by everyone. He just gets gifts, gifts, gifts all the time.



Both Amina and Warda report mobilising the support resources of family that live in countries other than England. Thus, the findings in this research support Finch's (2007) arguments that the notion of the family often transcends traditional definitions of social actors residing within the same household. On the contrary, carers often perceived support to be received by kinship ties across national boundaries. As such, these findings also support Zontini's (2006; 2010), study of Italian migrants living in Britain. She revealed that rather than being in decline, as some social capital theorists suggest, the family played an important and at times integral role in many of her respondents lives (for similar findings, also see Goulbourne *et al.*, 2010).

Findings in the data also suggested that carers who had migrated from other countries to Britain tended to construct tight-knit kinship groups over time. Mass migration of Muslims to Britain has a long history dating back to both World War I and World War II (Ansari, 2004; Ballard, 1994). Consequently, many British Muslim citizens have resided in Britain for many generations, building dense networks of family and kinship ties. This was reflected by many of the respondents in this study, who reported being supported by complex networks of family members residing in Britain. Ghaada provides an interesting example of a respondent who created a supportive family network through her children, who have now grown up and provide substantial support in her caring role. Ghaada moved from South Africa in the early 1970s. She

has four children, two of whom have learning disabilities. Her daughter with learning disabilities continues to live with her, whilst her son, who has learning disabilities and challenging behaviour, lives in a care home. She described her isolation when she first moved to England, especially as her husband was at work:

Like I said, we were living here. I am originally from South Africa so I couldn't go over there, they couldn't come over here. I had to make my home here. My husband was full-time at work, this was the Seventies, it not like what it is now. No, no break, I didn't know what a break was, I didn't know what a holiday was!

The feelings of isolation that Ghaada describes have been observed by numerous scholars who argue that the combined consequences of being a full-time carer and an ethnic minority in Britain can compound a sense of isolation (Ahmed and Jones, 2008; Atkin and Ahmed, 2000; Katbamna *et al.*, 2004; Katbamna *et al.*, 1999; Neufeld *et al.*, 2002; Spitzer *et al.*, 2003). However, Ghaada provides an example of how people migrating to Britain can develop positive family ties in their host country that can provide mobilisable resources of support. Ghaada's two remaining daughters have now grown up and live very close to her. One lives in a house opposite her own, and the other lives on an adjacent street. They have children of their own, however, Ghaada describes them as being integral to the care of their siblings:

My daughters are a great help, but nobody else. Nobody else understands them. My daughters are like second mothers to them [...]  
As they got older, they would give us a break. That's how we cope. My older daughter, she has got married and she lives opposite. My other daughter, she has two little ones and she lives on the main road. Not far from here. They are very close if I need them they come. They give me a break if I need to go somewhere.

These findings demonstrate how supportive family networks could be created within a range of diverse circumstances. This provides additional support to the argument that the Muslim family carers in this research were not a homogenous group: meanings of family support included relatives living within the same household (such as Quaniah), within the same street or geographical location (such as Tanweer or Ghaada), and across national boundaries in their countries of origin (such as Amina or Warda).

This subsection examined the family as a locus of support for the carers in the study. The findings suggest that the respondents generally perceive the family to form a significant aspect of their identities as Muslims, and cited comparisons between the perceived breakdown of the family in secular British society, with their own Muslim families. These findings echo arguments presented in Chapter Five, where a sense of religious identity was upheld by espousing negative beliefs about contemporary western society.

The subsection then focused on the practical ways that the respondents received help from family members. The findings here supported Finch's (2007) arguments that the concept of 'the family' can transcend family members living within the same household, and include relatives living within the local area and in different countries across the world. Consequently, how the respondents in the research experienced support was varied and diverse, giving support to the argument that the Muslim family carers in this study are not a homogenous group. The following subsection examines the diverse experiences of the family in more depth and argues that whilst it provided many of the carers in the study with support for their caring role, it could also be experienced as constraining due to the obligations and expectations espoused by some of the participants.

### **6.2.3 OBLIGATIONS AND EXPECTATIONS: EXPLORING THE 'DARK SIDE' OF THE FAMILY**

The previous subsection focused on how the carers in the study emphasised the positive aspects of belonging to family networks and ties, however, as Goulbourne *et al.* (2010: 137) argue 'the very same resources can be mobilized to have a much darker side'. As discussed above, many social capital theorists have argued that membership to strong ties and networks carries with it the implication of high social capital, however, these perspectives have been criticised for homogenising the complexities, rules and obligations of belonging (for a critical review see Edwards, 2004; Molyneux, 2002; Portes, 1998; Shah,

2007). Consequently, researchers are increasingly examining how the very same networks that provide resources can also inhibit a social actor's ability to access other benefits (e.g. Leonard, 2004; Zontini, 2006; 2010).

This subsection explores how, for some of the respondents in the study, beliefs about how care should be performed (often connected to religious and cultural expectations), may have constrained how support from outside the home could be accessed. Anthias's (2007) arguments pertaining to the mobilisability of resources are specifically implemented as a framework for exploring the participants' responses presented here. Additionally, Putnam's (2000) contribution to the distinction between 'bonding' and 'bridging' social capital is also employed as a means of exploring how the performance of care within the family (bonding social capital) was sometimes deemed incongruous with receiving support from outside the family (bridging social capital).

This subsection begins with a discussion about the expectations many respondents presented, that responsibilities of care should be kept within the family. Consequently, carers frequently presented accounts of how they currently undertake all aspects of care without the assistance of formal support organisations. The section then moves on to examine how these expectations are reconciled when caring circumstances require some medical or social intervention from an outside organisation. This dilemma revealed how the respondents often

presented contradictory accounts of support accessed. Here, most participants argued that they were not in receipt of any outside support, which seemed to contradict descriptions of services currently accessed. These accounts are analysed using Goffman's (1959) theories about *The Presentation of the Self in Everyday life*. They are followed by two fundamentally contrasting 'case studies', which attempt to contextualise the main argument of the subsection. In a nutshell this subsection argues that the Muslim family carers within this study are not a homogenised group, and their experiences of accessing support from both within the family and from outside organisations fundamentally differ depending upon the location of each social actor within the networks to which they belong.

Echoing some of the themes discussed in Chapter Four, many of the carers in the study described how they perceived their caring role to be a religious duty or obligation to the family. Some respondents also expressed concerns that these expectations would not be translated to future generations living in Britain. Nisha argued that:

With the Muslim community in this country, the times and generations that have passed, you have to look after your parents and then your children will look after you. But as we continue to live in the country we hope that this will still exist because the biggest carer for parents is the children and we just hope that stays as it has through the generations. Islam teaches you that you should look after your parents but I just

pray that continues (Nisha cares for her elderly father with physical disabilities).

These types of concerns were particularly prevalent for respondents caring for children with lifelong learning and/or physical disabilities. Here, participants were anxious about the care of their child after their own deaths. Meena cares for her son with severe learning and physical disabilities. She explained that due to her son being one of nine brothers and sisters, she expected that the performance of his care when she died would be easily shared out between siblings, however, due to her sons and daughters-in-law heavy work schedules, she is now concerned that the religious obligation to care for family members requiring support would not transpire. In the quote below Meena speaks in some detail about the religious duty to care for the family:

Interviewer: What do you think the options are for him when you aren't here? Who do you think will care for him?

Meena: I don't know. Maybe the brother or sister because in the absence of the mother or father, it is their responsibility. But in the end we can't force the responsibility to take care of him. You know, [in] my religion, everybody know is to just take care of the families, everybody, you know, all families, carry on – stick together, as Muslims we know that is our duty to take care of one another, however, it's not concrete, you don't know even if it's your own daughters, siblings, family members. They might not always fulfil that to the expectation, well, to

what is expected of them. They might not always fulfil the duty. We do tell them that 'look you do have some responsibility for the child' but whether they fulfil that is something else. They all know that brother is disabled, they all know [it is] their duty to look after him.

Similarly, Shereen argued that she rarely expects support for the care of her adult son with learning disabilities due to the work commitments of her daughters:

I have got daughters but I don't give pressure to anyone else because they are busy. I have my husband, he helps sometimes, but I am the main carer.

Consequently, she described how she prayed to *Allah* that her son would die one day before she did so he would not be required to live without her:

I have never regretted why this has happened to me. But the only thing is that I stay home and take care of him. This is the only thing that I pray to *Allah*, and that he can take him one day before me. He will listen to me because if he stayed after me then I don't know what would happen.

The concerns that Omera, Meena and Shereen voice have been similarly observed by scholars, who have pointed out that second and third generation British Muslims are increasingly integrating into the



norms of secular British culture. Consequently, Muslim women are marrying later, having children later and increasing their participation in the labour market (Ansari, 2004; Ballard, 1992, cited in Robertson Elliot, 1996). These changes influence the extent to which traditional family expectations of care, and the norms of reciprocating care between children and their parents, may be performed (for a more detailed discussions of these family negotiations see Finch, 1989; Finch and Mason, 1993; 1999). These findings are also echoed by Goulbourne *et al.* (2010) where a resistance to conform to the gendered and generational expectations and obligations for some respondents, at times led to a sense of shame and a breakdown of the relationship in the family.

The obligation to fulfil particular expectations of care was reported in complex and contradictory ways. The respondents regularly presented beliefs that care should ideally be undertaken solely within the home, however, certain circumstances often dictated that this was not possible. Furthermore, these beliefs seemed to have strong links to the notion that *Allah* had given their caring role as a test, and with it the tools to cope (this is discussed in more detail in Chapter Four).

Consequently, participants often spoke about how they undertook the care for a relative without any support from outside of the family. Leila cares for her husband with physical disabilities and her daughter with learning disabilities. Her perception that outside help would not provide the same standard of support was common theme within the data:

Leila: I care for my daughter and husband. They are both disabled and I look after them. I don't mind because it is my responsibility and I like caring for them. Neither my husband nor my daughter like it if anyone else cares for them. They want me to do it [...]

Interviewer: Would you benefit from more support?

Leila: I would benefit but my husband doesn't like it and I know their needs better and I know where everything [is] in the house so it is less trouble for me to do it.

These kinds of responses were often accompanied by a sense of pride that care could be undertaken without outside help. Omera provides a salient example of this type of account. She cared for her father-in-law before he died. She described how proud she was of the care she provided for him without outside support, and (similarly to Leila above) commented on how she thought that 'outside organisations' would not have been able to provide the same standard of care for her father-in-law:

I felt very good and rewarding, I never trusted anyone else, I never depended on anyone else until I didn't do it anymore. I feel that even if we had help from outside organisations, they wouldn't have cared as much in the way that I did. The love that I gave the care, I don't think anybody else could give that, although we knew there was support there I never used it, and I am very proud of that.

Ahmed and Rees Jones (2008) echo the findings above, in their study of female Bangladeshi carers in London. They argue that their respondents often reported a sense of religious (Islamic) duty to provide care, which placed constraints on seeking outside support. Moreover, respondents reported that they felt embarrassed to look for outside help because it may indicate to others that they had 'let traditional standards slip' (p.68). The sense of embarrassment at receiving support from outside the family was also observed in this research, in which respondents regularly presented contradictory accounts as to whether or not they were in receipt of any outside support. In this way, participants would often speak about their experiences of certain services they had accessed, after stating that they were not in receipt of any support.

In the exchange presented below Shereen describes how she does not receive any support for her caring role, stating that both her and her son do not like home help. However, an interruption to the interview conducted at Shereen's house, revealed that she currently receives respite support from a worker who comes to her home and provides activities for her son.

Interviewer: And how does caring make you feel?

Shereen: It is a hard job because you have to do everything but he doesn't, and I don't like the home help.

Interviewer: So do you get any help?

Shereen: No, no. We haven't asked for any help and he doesn't like [it]  
[...]

Interviewer: So you do feel like you are supported?

Shereen: Yes [Interruption and short exchange between Shereen and  
a woman who has entered the room].

Interviewer: Who is she?

Shereen: She is [name of woman], she works with [son's name]. They  
do what [son's name] wants. If he wants to go swimming then they  
take him swimming, if he wants to go out. September it will have been  
happening for two years. It's really good. After that I have felt really  
relaxed.

Interviewer: Do you trust who comes?

Shereen: Yes, there are a few others too. On Saturdays she will have  
him from ten o'clock until six o'clock. Sometimes we don't take  
advantage of it but [today] he is going boating with them until six  
o'clock.

A similar situation also arose in Hakim's interview, where he explained how he believed that God had given him the responsibility of care and that he does not receive any services, then subsequently spoke about the day care centre that his son regularly attends. Two separate extracts from Hakim's interview are presented below to demonstrate these accounts:

The God gives us and that is our responsibility. We feed them properly; not junk food, only twice a year we have chips at home. We eat Weetabix, wholemeal bread, lentils, fish once a week. We don't take any service, we don't want any money. I don't need anything.

[I am a] full-time carer: my son goes five times to day centre from nine until three. Weekend he is home and daughter is home. She doesn't go anywhere (Hakim cares for his adult son and daughter with learning disabilities).

Like Hakim, Eshmaal also described her caring role as a personal responsibility and explained how she solely provides care for her daughter with learning disabilities. In the quote below she is then asked if she has received any respite services. She replies that she has not, and subsequently explains the different forms of services that she has accessed.

Interviewer: How does being a carer make you feel?

Eshmaal: I see it as my responsibility to look after my kid and I don't rely on any other person, my family come but I do everything for her myself and she is very attached to me [...] she will say to anyone, 'no my mummy will do it for me, you don't do it'. Then I do it.

Interviewer: Have you had any respite care?

Eshmaal: No, none at all. The community nurse comes and OT [Occupational Therapy] and speech therapy [...] she was going to college for one year when she was 19 [...] In the summer holidays she was doing the play scheme and she was fine, painting, playing.

These types of responses formed a consistent theme throughout the data, wherein participants regularly stated that they received no outside support for their caring role, whilst also describing experiences of various services currently accessed. Goffman (1959) argues that in the act of presenting oneself, we offer an 'idealized view of the situation' (p.30), one which is "socialized", moulded and modified to fit into the understanding and expectations of the society' (p.30). In this way, we might understand the contradictory responses that many participants presented, as both a reflection of the expectations of being a Muslim family carer (undertaking care without support from outside the family), and a presentation of the lived circumstances of providing care for a family member (certain caring situations require additional support from outside the family). Furthermore, Ahmed and Rees Jones (2008) argue that the absence of traditional forms of support, such as large extended

families, rendered the Bangladeshi women in their research particularly prone to isolation. They argue:

This isolation appeared to be related to the expectations surrounding the duties of a Bangladeshi woman to undertake care, which was not necessarily backed up by the traditional forms of social support that might have previously accompanied such expectations (p.66).

Consequently, the findings seemed to suggest that the expectations of care provision for some of the carers in the study were at times incongruous with the needs and requirements of providing the best care for their chronically ill or disabled relative/s. For example, Tanweer cares for her husband in the advanced stages of Multiple Sclerosis. She explained how over the years she has gradually converted her house into a space that is appropriate for caring for her husband at home. In this way, Tanweer is able to both fulfil expectations of providing care from within the home and her religious duty to *Allah*, which was of particular importance to her. However, in practice, this process requires a significant amount of support from health and social services. Nurses and formal carers visit daily to assist in lifting her husband into a position where he can be washed. Furthermore, health professionals regularly visit to administer medication and perform medical procedures. Tanweer acknowledges the tensions of both providing care for her husband at home and accessing outside support in her account of a conversation with a social worker:

When the Asian social worker came to see us here she wasn't very helpful to be honest. Me thinking that being an Asian social worker, she may be able to understand my needs - like culturally and maybe our religious needs as well. Anyway, the thing she said to me which shocked me was 'as an Asian woman it is your duty like, and you should be looking after him' and I thought she shouldn't be saying this because one, she's a social worker and just because she is Asian – she has no right to say this to me and I complained to social services that I can't be dealing with somebody who is not going to be sympathetic really- telling me what to do just because I'm, you know, I'm Asian and a Muslim woman, that I should be looking after- oh yes it's my duty but it's not something that I have to do.

The strained relationship between attempts to provide the best form of care for a family member, and the expectation that care should be undertaken without outside support seemed to be exacerbated by the situational factors affecting the respondents. Here, the data seemed to suggest that the extent to which outside support was acceptably accessed was dependent upon the position of each social actor within the group. In this way, respondents with high social capital seemed to be able to mobilise the resources of outside organisations more successfully than those with low social capital. Putnam's (2000) bonding and bridging social capital becomes relevant here.

As highlighted in Chapter Two, Anthias (2007) criticises Putnam's (2000) bonding/bridging distinctions, arguing that it risks essentialising the experiences within and between groups. The findings here adhere



to Anthias's assertions, in that a social actor's experience of accessing resources outside of the family (bridging) seemed dependent upon the diverse positioning of the respondents within the family or community (bonding). Consequently, Anthias's criticisms of Putnam's distinctions allow a more nuanced perspective of how resources are mobilised within and between groups. The circumstances of two Muslim family carers interviewed for this research are presented as 'case studies' below as a means of exploring these arguments. Case Study One explores Ahmed, an elderly male carer of his adult son with learning disabilities. Case Study Two explores Rubina, an elderly female carer of her adult son with learning disabilities and challenging behaviour. Each participant will be discussed separately below. Further to this, a discussion will compare their circumstances.

#### ***6.2.3.1 Case Study One: Ahmed***

As described above, Ahmed cares for his adult son with learning disabilities. He lives in a large house in a predominantly Muslim populated area of the East Midlands with eight family members including his wife, two sons, their wives, and three grandchildren. Consistent with the findings in this research, Ahmed's role as a carer is heavily supported by his wife and daughters-in-law. He was accessed for interview through Bahir, a Muslim religious leader also interviewed for this research. She explained how she is acquainted with him as he is well known within the local Muslim community for donating his shop, which he worked in for fifty years, to be converted into a Mosque on his

retirement. Furthermore, his wife is a prominent figure within the local Muslim community, as she is one of only a handful of women who work at the local hospital preparing the dead bodies of Muslims according to the appropriate Islamic rituals.

Interviewer: Tell me a little bit about caring for [son's name].

Ahmed: He is a single person, mentally handicapped; he attends the regular day centre. Start half past eight in the morning and half past four he finish. He go by the coach and come back by the coach, they drop him at the door. They provide him dinners there and they look after very well. We all family look after him: me [the] father, mother, brother, sister-in-law and grandchild. All carry out for one person. We have lot of facility here and we have no problems with the social service or any other carer. We just carry on as we are because this is our child and he is now nearly fifty. We wash him, we shave him, we dress him up. He is not any problem [...] We do not feel any tiredness or anything else. All family just running.

Interviewer: Does your extended family live close by?

Ahmed: Very close. This family live in this one house. Eight people live in this house. This is a seven bedroom house and we all care for each other.

Interviewer: Is your son provided with *Halal* food at the day centre?

Ahmed: I would not be sure but they probably can't do that. As long as he is happy we are not concerning.

Interviewer: What do you do to relax?

Ahmed: I always relax. I do not do anything. Fifty years of work, now I can relax, she looks after me! [points to wife and laughs] [...]

Interviewer: What are the Muslim practices that you do with [son's name]?

Ahmed: We stay at home to do everything. But we have the Mosque down here. It used to be my shop but I gave it for them for free. I work free for the public every day. I don't take any penny.

Interviewer: Does a faith in Islam help [son's name]?

Ahmed: Yes. I know it is Islam. We go for *Hajj*. I go three times, my missus goes three times, my son, all family.

Interviewer: So you belong to a Mosque here. How does the Mosque and Imam support you and your family?

Ahmed: I support the Imam, he doesn't support me! [laughs]

#### **6.2.3.2 Case Study Two: Rubina**

As described above, Rubina cares for her adult son with learning disabilities and challenging behaviour. Her interview was fundamentally different from all other interviews undertaken in numerous ways. Firstly, Rubina was one of only two participants in the study whose child now resides in a care home. Rubina explained that she could not manage her son's severe behaviour. Secondly, Rubina is separated from her husband, and reported receiving no support from family and friends. Thirdly, Rubina was the only participant to report living alone. Finally, Rubina was the only respondent in the research that found it difficult to answer questions about her faith in Islam. At one point I offered to terminate the interview as it appeared that questions about her relationship to being Muslim was distressing, however, her interpreter suggested I asked the next question and the interview was concluded shortly afterwards.

Interviewer: What is a typical day caring for [son's name]?

Rubina: I sit down on the settee and watch TV. Tidies up all the house. She<sup>29</sup> doesn't actually care for him anymore because she couldn't manage him. He would get aggressive. So he has had to go into a care home. He is thirty-five [...] We bring him home once a week on Saturday and Sunday. He likes coming home [...]

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<sup>29</sup> Rubina's interview was undertaken with the use of an interpreter, however, she spoke enough English to directly answer some of the questions. Consequently, some passages of the transcript appear in the third person.

Interviewer: Do you have friends and family that you can talk to or support you?

Rubina: No. Other son is married off. Not really much support.

Interviewer: How does this make you feel?

Rubina: Helpless.

Interviewer: What do you do when you relax?

Rubina: Watching TV, lying down on bed settee. I never go out with family and friends.

Interviewer: Why not?

Rubina: I don't [...] He'd come Downstairs in the night, open all the windows and doors and put the TV on full volume. If I'd try to stop him he'd try to hit me.

Interviewer: This sounds very hard for you. Do you feel better knowing that he is in the home now?

Rubina: Not really, because I am mother, my son lives in a care home! Nice if he was at home [...]

Interviewer: What would be useful for him to have when he does come home at weekends?

Rubina: I could do with some financial support. Neither of them work.  
My husband not live with me. It is a long time that we separate.

Interviewer: So do you have to care for him when he comes home?

Rubina: Yes.

Interviewer: What does being Muslim mean to you?

[Long exchange between Rubina and Interpreter]

Interpreter: She saying 'what shall I say?' That's just cheeky – you  
have to tell her, not me.

[Further exchange between Rubina and Interpreter]

Rubina: I can't think [closes her eyes].

The case studies presented above were chosen on the grounds that they are obviously significantly different from each other. The aim of the remainder of this section is to use Ahmed and Rubina as examples to support my argument that the Muslim family carers in this research were differently located within the social networks to which they belonged, and this social location contributed to how easily support resources from outside the family were accessed. In other words, the extent to which a respondent was successful in mobilising resources into bonding social capital, contributed to how easily a carer could mobilise resources between groups into bridging social capital.

As discussed in Chapter Two, Bourdieu (1986) argued that of all the forms of capital, economic capital was the most valuable (Field, 2003; Siisiäinen, 2000). Additionally, he theorised that the subsequent forms of capital (cultural and social) were interchangeable and transferable with economic capital (see section 2.4.1 for a definition of Bourdieu's 'forms of capital'). Furthering Bourdieu's theories, Anthias (2007) argues that the value of economic capital lies in its transferability to resources, which often serves to symbolically represent a social actor's advantaged position within the group:

Indeed the value of the economic in itself lies in its transferability to a range of other resources which enable the achievement of life strategies. These include enjoying the prestige and honour, being able to wear designer clothes (if one aspires to this) or drive fashionable cars, living in a good area and sending children to private schools, to mention a few. These may have long term social mobility effects as well as allowing individuals to symbolically represent their social position, and allowing greater choice in social and personal life' (p.792).

In this way, it may be argued that Ahmed's interview suggested that he possessed economic capital, which he was able to transfer into both cultural capital and social capital. Moreover, Ahmed's economic capital was successfully transferred into resources that increased his access to further resources for bonding social capital. This process became apparent in two ways discussed below.

Primarily, it may be assumed that Ahmed's economic capital contributed to his ability to live in a large house, which in turn housed numerous family members able to contribute to the caring responsibilities of his son. Secondly, both Ahmed and his wife are well known and respected figures within the local Muslim community. Ahmed's donation of his shop to be converted into a Mosque, and his wife's specifically Muslim role at the local hospital has contributed to these reputations. Anthias (2007) argues that in order to successfully mobilise the resources of the group, one is required to pass as an 'appropriate ethnic subject' (p.797). In this way, it could be suggested that Ahmed's capacity to donate his shop acted as a transferral of economic capital into cultural capital, securing his reputation as an 'appropriate ethnic subject', or in this case, a 'good Muslim'. Consequently, it may be argued that his reputation as a 'good' Muslim allowed him to access support services outside of the family, even if they were not religiously appropriate (Ahmed doubted that his son received *Halal* food at the day centre), as they did not jeopardise his reputation or status as a 'good' Muslim, or his ability to receive support from his family. In other words, Ahmed's advantaged social position within the family and community (bonding social capital) contributed to the ease with which he reported accessing services outside the family (bridging social capital).

Rubina's interview painted a fundamentally different picture of how support resources were experienced and accessed. Using the same



theoretical framework used above to analyse Ahmed's interview, it may be argued that Rubina occupied a disadvantaged social position within the social networks to which she belongs. This became apparent in two ways discussed below.

Firstly, much existing literature argues that women are less successful in mobilising resources into social capital (Edwards, 2004; Molyneux, 2002; Lin, 2000). Moreover, the domestic division of labour continues to be fundamentally gendered (Finch and Mason, 1993; 1999; McKie *et al.*, 2004; Oakley, 1974; Sullivan, 2000), with responsibilities of caregiving largely remaining with women (Dalley, 1996; Lewis and Meredith, 1988). Rubina's interview was consistent with these findings. Separated from her husband, she reported undertaking the full responsibility of care for her son when he visits, without the support of any family members. Furthermore, the gendered beliefs and expectations espoused by many respondents regarding care as a religious duty to be undertaken within the home, was unable to be fulfilled by Rubina. Ahmed and Rees Jones (2008) refer to the sense of embarrassment felt by many carers in their study at the prospect of accessing outside support in that they perceived it as indicating that they had failed to cope and fulfil their Islamic duties. Perhaps this was why Rubina found some aspects of the interview difficult to engage with, however, these interpretations are only tentatively proposed. Nevertheless, her combined responses indicated that passing as a 'good' Muslim subject, with which to mobilise the support resources of

the family was somewhat unsuccessful, in that she explained that she was not in any receipt of support from her family.

Secondly, Rubina's interview suggested that, unlike Ahmed, she did not possess economic capital. She reported that both she and her husband were unemployed and extra financial state support would be beneficial. As such, Rubina was unable to transfer economic capital into any other form of capital with which to improve her seemingly isolated situation. Consequently, it may be argued that Rubina had access to very few resources with which to improve her caring circumstances, which she described feeling unhappy with. She reported dissatisfied feelings towards her son residing in a care home, arguing that she would like him to live at home, however, her economic and social circumstances limit her access to alternative arrangements.

Ahmed and Rubina's responses fundamentally differed in how they reported experiencing networks of support. Their contributions adhered to Anthias's (2007) assertions of social capital within ethnic groups in that their interviews suggested that the ability to mobilise support from within the family was dependent upon the positioning of each social actor within the network. Consequently, factors such as the possession of economic capital, gender and status within the community seemed to significantly contribute to the experience of accessing support both within the family (bonding) and from formal support organisations (bridging).

#### **6.2.4 SUMMARY**

This section explored the role of the family for the Muslim carers in this study. The data suggested that the family played a particularly important role for many respondents, and within these findings, three dominant themes emerged which were discussed as separate subsections above. Firstly, the family was examined in relation to how obligations of care were divided and allocated. This analysis revealed that caregiving seemed to be primarily divided along gender lines, with female respondents reporting undertaking the majority of caring responsibilities. Furthermore, respondents reported being supported by women in their caring role rendering men somewhat absent from accounts detailing the performance of care tasks. A 'hierarchy of caregiving' was proposed to explain both the gendered nature of performing care, and a further division of care labour observed between women within the family. Here, women married into the family seemed to be regularly cited by the carers in the study as undertaking a significant amount of care labour on behalf of the carer. The subsection concludes by arguing that further research is required to understand the care dynamics between relatives within Muslim families.

The second subsection examined how many respondents described the family as being of significant support for their caring role. Here, it was argued that the definitions of the family for many respondents transcended traditional conceptualisations of relatives living within a household (Finch, 2007). Respondents described support received from

relatives within the household, within the local area, and across national boundaries. These findings challenge arguments espoused by some social capital theorists that migration necessarily reduces social capital.

Thirdly, the final subsection explored the 'dark side' of the family, or the obligations and expectations that many carers expressed of providing care predominantly, if not exclusively from within the home, which at times seemed to constrain access to outside support. These tensions seemed more prevalent for a respondent whose relative's medical condition required the support of outside organisations.

Contradictions in the accounts of some respondents in the study as to whether or not they were currently in receipt of outside support for their caring role, provided additional strength to the argument that expectations of care (often based on notions of performing a Muslim duty) could be incompatible with the lived circumstances of providing the best form of care for a family member.

Consequently, it was argued that the social location of the Muslim family carers in this study within the networks to which they belong, contributed to how successfully resources for support were mobilised both within the family (bonding social capital) and when accessing formal support organisations (bridging social capital). An analysis of two respondents within the study suggested that these positionings could significantly diverge, leading to a final conclusion that the Muslim family carers in this study are not a homogenous group. Moreover, their

experiences of receiving support from within the family and from outside agencies were diverse, situational and depended upon a range of intersecting identities and circumstances.

The following section explores the role of four specifically Muslim carer support organisations, who initially acted as gatekeepers to accessing respondents for interview. However, their significant and positive presence in the carers' accounts revealed how they formed an integral role in how they received support and accessed health and social services.

### **6.3 'BRIDGING THE GAP': EXPLORING THE ROLE OF THE MUSLIM CARERS' ORGANISATION**

Carers accessed for interview were predominantly sampled from one of four specialist carers' organisations, where services were specifically aimed at supporting the distinct needs of Muslim family carers (see Table 4.2 for the spread of carers by organisational affiliation, and Section 3.5 for a description of each organisation). In response to this, I designed an interview question with a particular aim of eliciting the ways in which (if any) the organisation shaped or influenced their experiences as carers<sup>30</sup>. Responses to this question produced some interesting data pertaining to the positive and empowering role that the organisation had on its service users. Furthermore, the positive and supportive role of the

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<sup>30</sup> See Appendix 07 for the interview guide for carers.

carers' organisation was a salient theme throughout the interviews with both carers and professionals, not just in response to my questioning. Mitchell (1996a; 1996b) also observed the positive effects of belonging to a carer support group, and argues that more research needs to be carried out on exploring both how such groups are organised and the effects they have on their members. Further to this, Neufeld *et al.* (2002) argue that little research has mapped how immigrant female caregivers make connections to community resources for support. In response to these suggestions, this section explores how the carers in the study experienced belonging to a carers' organisation and how the structure of each group impacted on the types of responses given by the participants.

The section also includes responses elicited from a further fifteen interviews undertaken with professionals, whose occupation specifically relates to supporting Muslim family carers. In most cases, these interviews were conducted with staff, or associated professionals at the carers' organisations (see Table 4.7 for the spread of professionals interviewed), and their responses highlight and support the accounts given by the carers in the study, detailing the diverse requirements needed when attempting to 'bridge the gap' between Muslim family carers and state services. In this way, it will be argued that the Muslim carers' organisation regularly acted as a medium or 'bridge' between respondents and the successful mobilisation of formal state resources

of support into bridging social capital. This was achieved in numerous ways discussed below.

Parker (1990) in her classic work on informal care argues that 'conventional health and welfare services typically see the dependent person, rather than his or her carer, as their client. Any support 'which accrues to a carer is thus usually secondary, and often unintentional, result' (p. 95). Consequently, Parker (1990) argues that support groups aimed specifically at carers offer a valuable opportunity to share feelings and experiences with other people in the same position. However, the structure of a carer support group can significantly vary, making evaluations of its service provision arguably difficult (Mitchell, 1995a; Parker, 1990).

Two loose themes, based on Parker's (1990) arguments were observed within my data and will be discussed separately below. Firstly, all four organisations accessed provided a social environment, in which Muslim carers could socialise with each other in a religiously and culturally appropriate space. Secondly, three out of the four organisations accessed provided two further provisions for the purposes of the cared for relative. These services involved providing social activities for the cared for relative from within the organisation, and acted as a bridge or 'middleperson' between carers and available state services.

### **6.3.1 PROVISION OF SOCIAL ACTIVITIES IN A RELIGIOUSLY AND CULTURALLY APPROPRIATE SPACE**

Parker (1990) argues that membership to a carers' organisation can be a valuable experience for carers in that they can share emotional and moral support with other people in the same position. Similarly, in their study of support groups for carers of Dementia patients, Cuijpers *et al.* (1997) argue that affiliation to such organisations provide an opportunity to build new social networks with people experiencing similar circumstances. These findings were also echoed in this research, in which social activities hosted by the carers' organisation presented new opportunities to socialise, have fun and relax.

In all four organisations accessed, I observed that the provision of food seemed to be central to the meetings, and extended lunch and tea breaks provided space for members to socialise with other carers. For Organisation A, a meal provided every Saturday at lunchtime formed the basis of the group, from which other events or services would be discussed and organised. Similarly, Organisations B and C had food delivered at every meeting and a break for lunch could last over an hour. During this time members socialised and chatted with each other. Organisation D relied on the carers to provide food, which seemed to be the focus of much conversation during their extended tea breaks. When I visited, a member had made lamb samosas and yoghurt, which was extensively discussed by the staff and carers. The common theme that providing food seemed to share was that it created a social space with



which to interact with other carers and professionals. Both Leila and Vardah described the positive effects of socialising with carers.

Leila: The one thing is that you realise that you are not the only one going through this, you get to see other parents. It may not help me directly when parents tell me their experiences, [but I am] able to pick out bits. Say they have tried things and it didn't help, I make sure that I don't make the same mistakes (Leila cares for her husband with physical disabilities and her daughter with learning disabilities. She was accessed through Organisation B).

Vardah: [I]t opens your eyes up a bit more. So many children with more difficulty than my children, my girls. So it makes you more aware (Vardah cares for two adult daughters with mild learning disabilities. She was accessed through Organisation C).

The responses that Leila and Vardah present, reveal how involvement in the group provided their members with the opportunity to network with other carers, who could provide information and advice (see also Solomon *et al.*, 2001). Other carers spoke fondly of the events hosted by their organisation. These included (among others), shopping trips by mini-bus, *henna* painting sessions, art competitions and 'bring and buy' sales. Organised events seemed to provide carers with something to look forward to. At the time of data collection, Organisation B was preparing a shopping trip to a nearby city, which was the focus of much conversation in lunch breaks and between interviews. Below, Warda

describes a 'pampering' event and Dunia explains how she won a painting competition, both provided by Organisation C:

Warda: They made an event last year and it was so good. They were doing a massage in my head. It was just to relax. You ate there, there was music there. They gave me a massage and still now I remember, it relaxed me so much. I have never had this before, it was a massage in the head and it was so good! They do events like this and it is so good (Warda cares for her son with learning disabilities).

Dunia: With carer issues I think there is only Organisation C. Actually I won the painting competition. I used to do art when I was in my days at school but I stopped, I didn't take interest but I am going back into it now. Organisation C made me recognise that (Dunia cares for her son with severe physical and learning disabilities).

Solomon *et al.* (2001) also echoed these findings. In their study of mutual support groups for parents of children with disabilities, they found that belonging and being accepted in a social network where members can share emotions and feel more "normal" (p.126) was an important factor for many of their respondents. Moreover, for a group Solomon *et al.* recognise as being isolated, stigmatised and socially marginalised; the groups provided 'a unique experience of recognition, belonging, and of feeling valued' (p.126). These findings are pertinently demonstrated by Dunia, who further to winning a painting competition

(described above) gave a speech to the members of Organisation C, urging carers to interpret their caring role as a 'blessed thing':

I have given a talk with Organisation C with an audience. We went on the stage to collect [a trophy for winning an art competition hosted by Organisation C] and I wanted to say my bit that it is very important as a carer, it is a blessed thing. Don't be ashamed of it. I am trying to put that message across.

Similarly, Nisha, who cares for her elderly father described her attendance at Organisation D as 'a new place to look forward to and depend on. I know there is a new world and something there for me'. These accounts formed a consistent theme within the data, wherein membership to a carers' organisation seemed to increase confidence and provide events to look forward to and reflect fondly on. These findings are also consistent with literature on carer support groups (e.g. Cuijpers *et al.*, 1997; Mitchell, 1995a; Solomon *et al.*, 2001).

These findings here also reveal how the Muslim family carers in this study were able to receive support from a carers' organisation, despite the findings in the previous section suggesting that accessing outside organisations for support contradicted the expected nature of providing care solely from within the family (see also Ahmed and Rees Jones, 2008). Further analysis of the data suggested that the way in which each of the organisations was constructed blurred the boundary between the concept of receiving support from an 'outside organisation',

and receiving support from 'friends' within the Muslim community. This was achieved in two interrelated ways. Firstly, the organisations were distinctly informal in their approach to both accessing and relating to carers. Secondly, professionals at the services were attentive to the religious and cultural requirements of their service users. This is discussed in more detail below.

Respondents generally reported that their access to their respective carers' organisation and their relationship to the professionals at the service were informal, unofficial and often based on 'friendship'. For example, Vardah, who cares for two adult daughters with mild learning disabilities, spoke about how she became a member of Organisation C through her neighbour, who is the current manager of the group explaining '[w]ell I know Abida [manager of Organisation C], she is my neighbour. So she started it all and told me to come along'. Similarly, Fuseelah described how she explained to her daughter with learning disabilities that the employees at Organisation C were her friends:

Basically I tell her that she does have friends, you have got your cousins next door, I am your friend, Abida [manager of Organisation C] is your friend. She gets on well with one or two at Organisation C so I say see you have got friends there as well.

These findings echo Hepworth's (2005) study of South Asian carers' perceptions of support in the community. He found that the concept of 'friendship' was important to some of the respondents in his research,

where carers sometimes opted to maintain relationships with professionals that they had come to consider as friends rather than establishing a formal link with other workers. These findings contrast with those in Mitchell's (1996a) study of carer support groups, in which respondents generally reported actively joining the group to obtain information from the professional workers and invited speakers.

The professionals interviewed for this research, and who worked at the carers' organisations reported being aware of the sensitivities surrounding accessing support, and the need to provide services that were local, informal and familial. Jaya, the manager of Organisation D displayed a succinct understanding of the complexities associated with accessing social services within Muslim families and argued that the success of her group was based on the notion that it was like 'family', due to their close connection with the community:

[T]he biggest thing is the stigma of being able to cope yourself if you can't cope yourself what sort of person are you if you can't look after your mother-in-law or your father-in-law or you've put them in a home, you know, you've dishonoured the family. If your child's got a disability and you've got somebody looking after your child [then people think] 'can't you even do that for your child?' It will be things like that and what tends to happen with- especially with Muslim families [...]

[B]ecause our service is culturally appropriate and language appropriate it's not too big a thing because it's like letting them out with

family so we don't have a problem with them accessing our services at all because we just seem like part of the community.

Fawaz also displayed a detailed understanding of the gaps in Muslim family carers receiving support. He owns the building that Organisation B operates from. The building has been converted into numerous specifically Muslim groups addressing issues such as youth, domestic violence, disability and carers. He echoed existing literature suggesting that the gradual breakdown of the extended Muslim family has placed extra pressure on carers (Ahmed and Rees Jones, 2008; Ansari, 2004):

[T]here are still significant gaps and there are still some cultural barriers to seeking help from external and professional sources, the Muslim extended family traditions which catered for these needs are breaking down gradually in this country and we are returning – well not returning but getting to a stage where our families are becoming more nuclear than extended and so there are more heavier demands on the carers who are on their own without that extended family support and do need to be connected with sources of support and here at Organisation B the carers came together themselves, formed Organisation B carers group, which you are visiting today and they have made significant progress in sharing their sort of needs and their requirements, their thoughts, and there is quite a bit of activity that goes on.

Ghatsaan, a social worker who manages Organisation B, also demonstrated an understanding of the complexities surrounding Muslim

carers accessing support. He explained his observations about the importance of creating a religiously and culturally appropriate service wherein Muslim carers could be adequately supported. Moreover, considering the sensitivities surrounding keeping men and women separate (*purdah*), Ghatsaan perceived the need to employ a female development worker, specifically employed on the basis that she understands the religious and cultural sensitivities of Muslim family carers:

In [specific West Midlands area] the largest minority group is Pakistani Muslim and they are the least likely to access services because of language issues, culture, some issues around faith and gender, you know, faith and the implications of gender there. I made a case to my senior manager that we employ a woman worker because I am a male. Now my real concern was that the vast majority of carers are women and I can't engage with them on an emotional level, if they want to a shoulder to cry on then I can't really support them [...] My worry was that if we asked for someone of a Muslim background then we might get someone from an Indian background or someone who was African Caribbean who may not be able to communicate with the carers who are from a Pakistani Mipuri background, who may not be able to communicate in their first language, may not understand their cultural and religious sensitivities.

Ghatsaan's experiences echo the findings in Mitchell's (1996b) study, where ideas for carer support groups often developed out of a social workers contact with vulnerable people and their families, and the

perceived need for a specific service. Consequently, Mitchell (1996b) argues that carer support groups facilitated by social workers often resulted in them carrying out a range of tasks in a manner that was informal, friendly, supportive, and enabling (p. 49). These findings were also observed in this study, where employees were often required to transcend the boundary of what some would consider to be a 'professional relationship'. Here, being part of the local Muslim community often meant being available for support at unconventional times of the day. Ghatsaan described how his recognition of the need for a female development worker led to her being in high demand by the service users, often late at night:

Some families wouldn't be happy for me to provide that one to one support to their daughters. And also the emotional needs that mothers have, I'm not the right person to do that [...] I mean [name of service user] was calling her [female development worker] up at 11 o'clock at night. Clearly if that was me she wouldn't be doing that. I am a male social worker, clearly there are sensitivities around gender and all that (Ghatsaan is the current manager of Organisation B).

These findings provide an important insight into how the Muslim carers' organisations accessed for this research both recognised and responded to the religious and cultural requirements of their service users. As such, it provided a space where carers felt comfortable to access support and respite without compromising their religious



identities. As Eshmaal reflected when asked about her relationship with Organisation C:

Interviewer: How helpful have [Organisation C] been for you?

Eshmaal: Very helpful because they have the separate groups. The ladies separate and the boys separate. Her [daughter] problem is that she won't go there, she won't come. I have tried to take her but she is not willing to come with me. If somebody else can come and take her even for an hour and sit and do painting or crafts. Even the day centres they are all mixed [sexes] in the social services (Eshmaal cares for her daughter with learning disabilities).

As described in Chapter Five, the importance that Eshmaal placed on her daughter receiving separate services from men has resulted in her currently not receiving any social activities outside the home.

Consequently, Organisation C's attention to providing services specifically suitable to Muslim carers resulted in Eshmaal positively encouraging her daughter to attend the group. These kinds of responses starkly contrast with the types of accounts presented in Chapter Five. Here, girls with learning disabilities were generally prevented and discouraged from accessing social services.

This subsection examined how the Muslim carers' organisations accessed for this research were able to provide many of the carers in the study with social activities and respite from their caring role in a

religiously and culturally appropriate space that did not jeopardise their religious identities. This was achieved by recognising the complexities surrounding providing care within Muslim families, and the associated obligations and expectations to undertake care without the support of outside organisations. The following subsection explores how the carers' organisations also provided a further service, where activities were provided for the cared for relative from within the Muslim carers' organisation that the carers had come to trust. Furthermore, the groups often acted as a medium between their service users and social services.

#### **6.3.2 ACCESSING SOCIAL SERVICES: BRIDGING SOCIAL CAPITAL AND THE ROLE OF THE MUSLIM CARERS' ORGANISATION**

This subsection explores how three out of the four Muslim carer support organisations accessed provided two additional services for their members. Firstly, group members were offered social activities for their cared for relatives from within the organisation. In this way, the trust built between the organisation and the service user allowed access to the cared for relative in the knowledge that their religious and cultural requirements would be met. Secondly, the organisation mediated and negotiated access to health and social services on behalf of the carer. Professionals at the organisation regularly reported that they conceptualised their occupation as providing a 'bridge' between Muslim family carers and their access to services. These accounts provide a particularly interesting insight into how involvement with a Muslim

carers' organisation may act as an available and mobilisable resource into bridging social capital. These forms of support are discussed separately below.

Organisations B, C and D<sup>31</sup> all provided additional services to the carer support groups described above. Here, activities were offered to the cared for relatives of carers within the group. In all three organisations this seemed to be a new facility, however, the respondents in the study received the service positively. For example, when Iqraam, who cares for three adult sons with learning disabilities, was asked about his thoughts on Organisation B, he replied by speaking about the additional service that provides activities for his son:

Interviewer: How does Organisation B support you and make you feel?

Iqraam: First thing he<sup>32</sup> mentioned was the [group name for cared for relatives] but that is not Organisation B. They take him [son] out and things like that.

Interviewer: Oh is this one of your sons?

Iqraam: Yes, because [son's name] comes to [group name for cared for relatives] and eh, that helps but I did say that we are kind of sister

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<sup>31</sup> At the time of data collection, Organisation A was experiencing funding difficulties. Consequently, they were only able to provide a meal every Saturday for carers and their cared for relatives. The nature of each carer group is described in more detail in section 3.5.1.

<sup>32</sup> Iqraam's interview was carried out with the use of an interpreter. Consequently, some passages of the interview transcript appears in the third person.

projects and Organisation B is something else. He says that with Organisation B your knowledge expands each time you come here you learn something new and go back with something that you didn't come with so that's that.

This additional service to the carers' organisation provided the cared for relatives in the study access to activities outside of the home. This was principally important for the particularly isolated service users. As Fuseelah, who cares for her daughter with mild learning disabilities described: 'before, she [her daughter] was in the house twenty-four seven, but with Organisation C she goes out, and through them we tend to keep in touch with the city council and the social services'. In Fuseelah's response she also refers to the second additional service that Organisation B, C and D provided. This is discussed in more detail below.

Organisation B, C and D also acted as a medium between Muslim family carers and their access to health and social services. These types of services are a regular addition to a carer support group. As Mitchell (1996b) points out, carer groups, supported by professionals can often be helpful in linking carers with service providers. This was a particularly salient theme here, where respondents regularly spoke about how they both accessed and negotiated social services in particular through their membership to the carers' organisation. For example, Yalina cares for two children with severe learning and

physical disabilities. She described how Organisation B supported her in providing forms:

I think it is brilliant. Even though I know English I still get support here because even ordering forms and things, I don't need to do that, I just need to drop in and ask them for a form and they have it for me in a jiffy. But if I had to sit on the phone all day and say 'can I have this form please, can I have that form please?' I can't get nothing done so Organisation B is one of the best things around. And we need more Organisation B's everywhere.

Umina also demonstrated the benefits of her affiliation to Organisation C. She described how her daughter with Down's syndrome was excluded from going swimming with the rest of her school due to her allegedly soiling the pool in a previous visit. Umina explained how she was dissatisfied with this arrangement so contacted Organisation C, who, at the time of data collection, were in the process of resolving the issue on her behalf:

I did have a problem with the swimming. The people said that she wasn't allowed to go because the last time she went she made a mess and because of that they had to take all the kids out and this and that. I told the school, why is she doing a mess at school and not at home? I want to know the reason why [...] They said they don't understand so they can't take her swimming [...] It can't be that the whole class goes and she is left with another class. That is not good [...] so we went via Organisation C as to what we can do about it; to get information. We

went today to see the lady and they gave us guidance and will speak to them for us.

Similarly, Fuseelah, who cares for her daughter with mild learning disabilities described how her involvement with Organisation C led to paid employment for her daughter. Here, the organisation's link with local council initiatives to include people with learning disabilities in employment led to Fuseelah's daughter successfully applying for the position:

Organisation C has jobs available for people with learning disabilities. It is only three hours a week, so she applied and she got the job. She is very proud of it; she has just been to her second supervision this morning. She assists the [name] department. So she is working with that team and she is very happy about it. It is not fixed, three hours a week, she only needs to go when she needs to, if they have a meeting. Now she is very confident with the meeting and next week she going to help the lady in the meeting. It has made a big difference to her because now she doesn't think that her sister has got everything because of the disability.

These findings reveal the positive ways in which the carers' organisations were able to fill the gaps between carers and their access to social services for their cared for relatives. The professionals interviewed for this study illuminated the ways in which their services constructed innovative methods for increasing access to social

services. The remainder of this section focuses on these accounts and provides a discussion of the findings.

The professionals interviewed for this study were united in their belief that Muslim family carers required specific services that were religiously and culturally appropriate, and that this support was not available, echoing the arguments espoused by many researchers of South Asian carers (e.g. Atkin *et al.*, 2002; Katbamna *et al.*, 2004). Consequently, these organisations reported constructing innovative access strategies that would ‘bridge the gap’ between Muslim carers and available services, without the carers needing to jeopardise the honour (*izzat*) of their disabled cared for relatives (Hussain, 2005). For example, Jaya, the current manager of Organisation D, explained how they provide IT and English classes for their service users. However, due to sensitivities surrounding mixed groups (*purdah*), the classes are undertaken in two separate rooms at once. Here, carers choose whether or not their cared for relative sits in the mixed sex classroom, or the female only room. As such, Jaya described how the carers at Organisation D consider sending their chronically ill and disabled relatives to the service as ‘no big deal’.

Similarly, Inaam, one of the founders of Organisation C described how their service attempts to learn about religious and cultural requirements from the group members, so that they can subsequently liaise with

social services on their behalf. In this way, Inaam describes Organisation C as 'bridging the gap' between carers and services:

We have to respect beliefs and we want to respect that and it's up to families to teach us and for us to learn from them, you know, groups like Organisation C are key to breaking down those barriers 'cos they interact with statutory services and other organisations so groups like that are key to try to *bridge that gap* (my emphasis).

Kaleemah also conceptualised her role as mediating between carers and services. At the time of data collection Kaleemah was employed as a development worker for Organisation B. She explained how she had been running a pilot scheme, where she travelled with disabled Muslim girls to a day care centre, oversaw that they did not interact with other male service users and then escorted them home. She described that her knowledge of the cultural beliefs of her service users meant that she acted as a 'middle person' between carers and professional support:

Professionals have great level of difficulty interacting with families because carers have their own cultural beliefs, for example if they are displaying challenging behaviour, you know they don't know why they are displaying challenging behaviour [...] So it is a two way process. *I am the middle person and the main person who creates the communication between the professionals and the carers.* Whereas if there is no support they will just sit at home and try to cope [...] that's where most of our carers suffer from depression, anxiety and stress.



Because first they can't understand the system, second the language barrier, and they haven't got the support [my emphasis].

The mediating and 'bridging' role between carers and services that the professionals in the study regularly reported, reveal the ways in which the Muslim carers' organisation afforded their service users opportunities to access social services without jeopardising their religious identities. Moreover, it may be argued that the carers' organisation acted as the mobilising force with which to transfer services into bridging social capital. This is discussed in more detail below.

The previous section explored how the complexities surrounding caregiving within Muslim families often problematised access to formal services that could support respondents in their caring role. Consequently, it may be argued that state run services were only available to respondents in theory. Here, the possible negative consequences of accessing 'outside organisations' rendered their provision as somewhat arbitrary for many of the carers in the study. As Anthias (2007: 788) argues, resources can only be considered to be social capital if they are mobilisable for the pursuit of advantage, or the mitigation of disadvantage. If 'outside organisations' are inaccessible to some Muslim family carers due to the situational circumstances within the networks to which they belong (bonding social capital), then they cannot usefully be considered to be available bridging social capital.

Leonard (2004), in her study of bonding and bridging social capital in Belfast also noted the complex and problematic relationship between bonding social capital and bridging social capital. Echoing Anthias (2007), Leonard (2004) argues that Putnam's (2000) bridging/bonding distinctions are too simplistic, failing to account for the complexities within and between social networks. Her findings revealed that high bonding social capital within communities in Belfast often problematised bridging social capital. Here, high levels of distrust of wider institutions reinforced the bonds within communities. Consequently, Leonard (2004: 941) argues that:

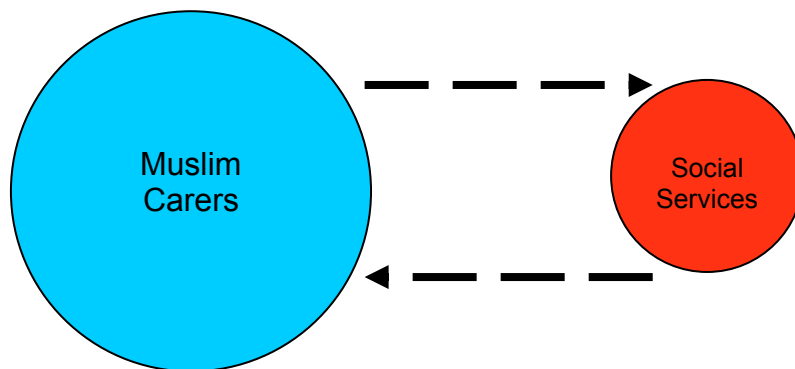
Building bridges necessitates removing the grounds that were conducive to creating linkages among those most disaffected by the wider political system. While Putnam rightly highlights the exclusive nature of bonding social capital, providing inclusive bridging capital is no easy task and may be achieved at the expense of groups once able to call on bonding social capital.

The findings in this research echo Leonard's arguments and situate the Muslim carers' organisation as a particularly important mediating presence in the accumulation of bridging social capital for the carers in the study. Figure 6.1 attempts to visually represent this argument. The diagram attempts to depict how the Muslim carers' organisation provided a solution to the gaps in access to social services for some of the respondents in this study. It presents three situations to make this point.

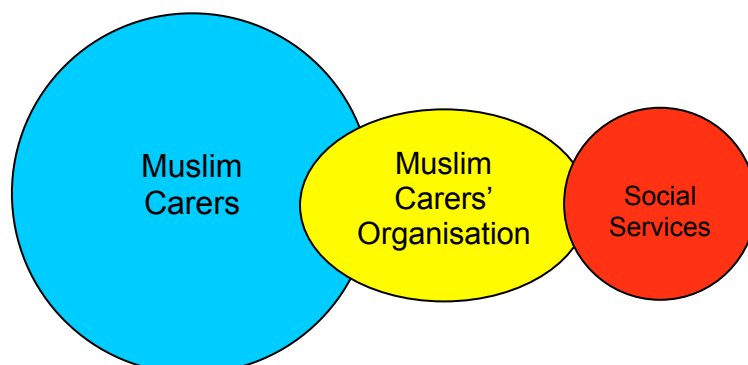
**Figure 6.1: Three Relationships to Social Services**



*Relationship A: an unproblematic relationship to Social Services*



*Relationship B: a problematic relationship to social services as experienced by many respondents in this study*



*Relationship C: The mediating or 'bridging' role of a Muslim carers' organisation*

Relationship A depicts an idealised circumstance with which a carer makes use of social services. Here, the carer is culturally located within mainstream British society, therefore, access to state resources such as social services does not necessarily challenge core aspects of the carers cultural identity, and social services form a useful and unproblematic aspect of a carer's support networks. This aspect of the diagram does not attempt to homogenise the experiences of non-Muslim carers. On the contrary, I fully acknowledge the range of intersecting factors and circumstances that construct a carer's situation, which may result in a problematic relationship to social services.

Relationship A is merely presented as a precursor to Relationship B, which depicts the circumstances of many of the carers in this study. Here, carers and social services occupy different cultural spaces. The respondents are informed by Muslim cultural practices, which (as Chapter Five explored) are often incongruous with the cultural practices of mainstream British social services. Consequently, a carer is required to transcend (or bridge) a symbolic cultural boundary to access social services. This often challenges core aspects of a carer's religious and cultural identity. The broken arrows symbolise how respondents often attempted access in problematic, controlled and managed ways.

Relationship C depicts how the Muslim carers' organisation occupies the space between Muslim family carers and social services.

Consequently, the carers are not required to transcend the cultural

boundaries that demarcate ethnic differences and uphold religious identities. Instead, the carers' organisations work with carers within the cultural spaces to which they occupy. In this way, it negotiates cultural boundaries on behalf of the carer, as Kaleemah, a development worker at Organisation B indicated:

I understand what they are thinking, what they are saying and they relate to me with expectations of 'you should know our religions and our beliefs'. And then when I make a decision that is not quite according to our beliefs then they get really upset because they have certain expectations from me so in a way it is very close to my identity because my beliefs are linked to their beliefs and that reflects upon my professional work. Whatever I do I bear in mind their religious beliefs and the culture and then I make a decision.

In this way, the carers' organisation acts as the 'bridging' force on behalf of the Muslim family carers in the study, many of whom would otherwise be unable to mobilise social services into available support. Consequently, it may be argued that the organisations acted as a mobilising force with which many of the carers in the study were able to transfer resources (social services) into bridging social capital, without compromising bonding social capital within the networks to which they belong (e.g. the family or community).

### **6.3.3 SUMMARY**

This section explored the role of four specifically Muslim carer support organisations. It examined how they provided two loosely related services for its members. Firstly, specific knowledge of the gendered religious and cultural expectations and obligations of Muslim family carers led to these organisations being able to provide carers with a religiously and culturally appropriate space within which to socialise with other carers, relax and have a break from their often demanding caring circumstances.

Secondly, two additional services provided by Organisations B, C and D pertaining to social activities and services for the cared for relative were also positively received by the respondents in this study. Social activities provided by the organisation were a relatively new addition to the carer groups, however, respondents spoke positively about these facilities, and professionals described how their attention to the religious and cultural requirements of their service users rendered these services an important addition to the group.

The carers in the study also regularly spoke about how the carers' organisation negotiated access to state services on their behalf. This was more regularly spoken about in relation to social services. Here, professionals at the services often perceived themselves as playing a mediating or bridging role for Muslim family carers. In this way, the gaps

in access to social services were bridged by the organisation, so carers were not required to transcend the religious and cultural boundaries, which served to demarcate ethnic boundaries and uphold religious identities. In this way, the carers' organisation constructed innovative methods wherein the support resources of social services could be successfully mobilised by the carers in the study into bridging social capital, without jeopardising the resources of support received within the networks to which they belong (bonding social capital).

Unfortunately, very little research explores the dynamics of carer support groups. This factor has also been acknowledged by Mitchell (1996a), however, in the fifteen years since his paper was accepted for publication, it would seem that this shortage continues, especially for South Asian and Muslim carers. Consequently, I argue that further research pertaining to the role of carer support organisations is needed. This is discussed in more detail in Chapter Seven.

## **6.4 CONCLUSION**

Social capital provides an increasingly popular conceptual tool with which to understand social networks, ties and kinship groups (Field, 2003; Halpern, 2005). Within this chapter, it provided a useful framework for understanding how the respondents' social networks could be used for support, but also be the source of expectation, obligation and conflict. The findings suggested that the family formed an

important social network for the respondents in the study. This is consistent with existing literature on care, wherein scholars have examined how constructions of the family play a key role in shaping the experiences of both caregiver and care receiver (see Phillips, 2007 for a detailed discussion of this literature). Here, caregiving and support for a carer was fundamentally gendered, however, a further division of labour between women was also observed. Women married into the family seemed to take on many responsibilities of care. Consequently, the findings adhere to Finch and Mason's (1993) assertions that negotiations of family responsibilities are dependent upon the position of each social actor within the family network.

Although the family was an important source of support for many of the carers in the study, religious and cultural expectations that care should be provided from within the family, and without the support of outside organisations rendered access to formal support as somewhat problematic. This was innovatively challenged by four carers' organisations who acted as gatekeepers to the majority of carers in the study. In this way, providing a mediating or 'bridging' force between carers and available social services allowed respondents to receive formal support for their caring role without jeopardising their religious and cultural identities. As such, this chapter provides important information for service providers pertaining to how Muslim family carers may be successfully accessed by formal state services for support within their caring role.



## **CHAPTER SEVEN**

### **CONCLUSION**

#### **7.1 INTRODUCTION**

This thesis set out to explore how Muslim family carers of chronically ill or disabled family members perceived, performed and negotiated their caring responsibilities. More specifically, it looked for similarities and differences in the carers' accounts, and identified patterns that contributed to an understanding of how being Muslim significantly shaped how caring was undertaken within the family.

The thesis focused on how religious beliefs, based within Muslim traditions, were constructed as a way of both providing comfort and support in the face of often difficult circumstances, and granted spiritual significance to daily routines of caregiving. It explored the complex implementation of symbolic boundaries, which demarcated the lines between 'pure' and 'dangerous' spaces outside of the home. Consequently, it revealed how health services were generally positively received and accessed, however, difficulties arose in the uptake of social services, primarily due to the threat they posed to the reputation and honour of the family (*izzat*). Finally it explored how the carers primarily received support from the family and the Muslim carers' organisation. This analysis revealed the complexity of belonging to

social networks, which were constructed hierarchically, and dependent upon a range of factors including gender, economic class, status, and one's reputation as a 'good' Muslim subject (Anthias, 2007). As such, access to the support resources of such ties was dependent upon the position of each social actor within the group.

This chapter will discuss the wider outcomes of this research by drawing together and critically examining the overall findings within the context of existing literature. It will assess the contribution of these findings to different fields of knowledge, make suggestions for further research, and reflect on the thesis as a whole.

## **7.2 CONCEPTUAL THEMES AND ORIGINAL CONTRIBUTIONS TO KNOWLEDGE**

This section explores the empirical themes that emerged within the data chapters to discuss a variety of conceptual and theoretical issues.

These themes are examined under the following headings: 'The Salience of Religious Faith in Everyday Care', 'Purity and Danger', and 'Social Capital: The Family, Gender and Caring'. A further shorter subsection is also presented entitled 'Potential Contributions to Policy Development and Service Provision', as it makes suggestions for how the findings in the data could be utilised by policy makers and service providers.

### 7.2.1 THE SALIENCE OF RELIGIOUS FAITH IN EVERYDAY CARE

As articulated in Chapter Two, existing studies of care, disability, religion, and spirituality have overwhelmingly argued that religious belief significantly and positively influences people's experiences of caring for a chronically ill or disabled family member (Bennett *et al.* 1995; Dollahite, 2003; Poston and Turnbull, 2004; Skinner *et al.* 2001; Treloar, 2002). The findings in this study adhered to this body of research, whereby religious faith formed a significant and positive role for the carers in the study. This research also adds to knowledge within this body of literature in two ways. Firstly, it specifically focuses on Muslim family carers. As a large proportion of sociological studies have explored religious carers of Christian denominations, this research provides an important insight into the role of religion for Muslim carers. Secondly, the conceptual frameworks applied to the data allowed an analysis of both the positive effects of constructing religious beliefs about care, illness and disability, but also *how* these beliefs were constructed. This is discussed in more detail below.

The significance attributed to the respondents' identities as Muslims is also echoed within existing literature on British Muslims (Ansari, 2004; Ballard, 1994; Modood, 2003). Not only did the practice of Muslim rituals, such as praying, fasting or reading the *Qur'an* form an integral part of the respondents' everyday routines, but a belief in the omnipotence of *Allah* gave important spiritual significance and meaning to their caring role. In this way, it may be argued that trust in a divine

plan controlled by *Allah* constructed a comforting 'sacred canopy' through which meaning could be attributed to a carer's sometimes difficult and demanding circumstances.

Berger (1967) conceptualises a 'sacred canopy' through which an overarching framework of meaning gives spiritual significance to the practical day-to-day routines of everyday life. In this way, situations, circumstances and events appear to be part of a larger purpose. The findings in this study add to this body of knowledge by exploring how the construction of a 'sacred canopy' comforted and supported the carers, through which positive meanings were attributed to the lived experiences of their caring circumstances. Such beliefs may be interpreted as 'theodicies', and Weber's (1922) theoretical contribution to debates surrounding theodicy were interestingly applied to this research.

The concept of theodicy has seldom been applied to modern studies pertaining to the construction of religious belief in the face of misfortune and suffering, despite continued support of its relevance from scholars within the sociology of religion (e.g. Moschella *et al.*, 1997; Musick, 2000; Turner, 1981). Weber's (1922) theoretical contributions to theodicy were applied here as an analytical tool for understanding these beliefs. His categorisation of theodological beliefs into three groups of pure type solutions to the problem of theodicy could only partly account for how the respondents presented their own beliefs about suffering and misfortune.

Weber's (1922) concept of theodicy provides an important tool for understanding the complexity and inconsistencies in the construction of beliefs pertaining to a carer's circumstances. In this way, theodicies were based in popular Muslim theology, but reconstructed by the respondents as a response to their individual circumstances (Ammerman, 2007). Beliefs were not distinctively divided between the pure type solutions, but rather tended to borrow the most reassuring and comforting aspects of each. Accordingly, Weber's second pure type, or the belief in the eternal battle between good and evil was distinctly absent from the carers' accounts, as the uptake of negative beliefs such as 'evil' may be incongruous with positive psychosocial coping strategies.

The sociology of religion has experienced a dramatic shift in focus over the past twenty years (Ammerman, 2007) from being primarily concerned with the institutional aspects of religious adherence, sociologists are increasingly focusing on how religion is experienced within peoples' everyday lives. As Aldridge (2007) points out, classical sociological theories of religion tended to be concerned with replacing religious belief with western scientific rationalism. Consequently, he urges contemporary researchers of the sociology of religion to exercise caution when applying classical theory to their studies. This research builds an interesting bridge between classical sociology and modern conceptualisations of religion. By implementing the concept of Weber's (1922) theodicy as a theoretical framework for analysing the

respondents' beliefs about their caring circumstances, this research was able to explore the complexities, inconsistencies and selectivity in the construction of religious beliefs about care, illness and disability. Consequently, the study was able to draw together elements of classical sociology of religion with modern conceptualisations that value the lived, and private experiences of everyday religious life. In this way, one can see how Weber's concepts of theodicy continue to have relevance within modern studies of religion.

Scholars such as McGuire (2007; 2008), Ammerman (2007), Beckford (2003), and Davie (1994; 2000; 2004) have argued that valuing the private, lived and everyday religious beliefs of ordinary people (rather than official spokespersons) reveals the continued relevance of faith in contemporary society. Moreover, they assert that focusing on these religious beliefs allows for an analysis of how religion is employed as a cultural resource for aspects of identity and commitment.

Both McGuire (2008) and Ammerman (2007) argue that 'lived' or everyday religion is often based in orthodox religious belief, but creatively adapted, re-constructed and shaped around the situational circumstances of individual people. McGuire (2008) argues that rather than treat these beliefs as 'defective, ignorant, or inferior versions of church religiosity, we should take these elements more seriously' (p. 48). Taking seriously the respondents 'lived' religious beliefs in this study led to an understanding of how faith could serve to generate

'spiritual capital'. Here, respondents gleaned benefits from investing in religious beliefs about their caring role. Consequently, beliefs about the sacred nature of care, health, illness and disability served to reinforce that the respondents' day-to-day routines had both spiritual significance and would be positively rewarded in the afterlife. Finke (2003) argues that spiritual capital provides a useful conceptual framework for understanding how satisfaction is drawn from investing in religious activities. He asserts:

Religious activities such as prayers, rituals, miracles, and mystical experiences, build up over a lifetime, not only increasing confidence in the truth of a religion, but strengthening emotional ties to a specific religion. Together these emotional attachments and the mastering of a religion become investments that build up over time and constitute religious capital. This capital helps to explain the religious activity and satisfaction of individuals (p.3).

Sociological studies of religion and care generally concur that religious beliefs positively support carers and contribute to constructive coping strategies. These studies now need to go beyond these basic findings and question how these religious beliefs are constructed within the lived circumstances of everyday life. Therefore, this research suggests that questions need to be asked about the diversity of religious beliefs between respondents to provide a more nuanced understanding of the intersections between religious belief and other salient identities such as gender, age, economic class, and disability.

### 7.2.2 PURITY AND DANGER

Existing literature suggests that minority ethnic carers, particularly those from South Asian origin experience a range of institutional barriers that prevent access to state services (Atkin *et al.*, 2002; Hussain, 2005; Katbamna *et al.*, 2004). The findings in this research adhere to this body of literature, whilst providing additional insight into how Muslim family carers may control access to some services in an attempt to uphold a sense of religious and cultural identity. Here, respondents regularly referred to entry into certain state services as being 'risky', unclean and dangerous. As such, the conceptual framework that the binary dualism 'purity and danger' offers was interestingly applied to these accounts. This is explored in more detail below.

Scholars have documented how the ethnic and religious identity of a minority group can heighten as a cultural defence in an ethnically and religiously different society (Ammerman, 2003; Yip, 2005). My research adds to existing knowledge about how this shapes perceptions of, and negotiations with state services. Mary Douglas (1966) in her seminal work on *Purity and Danger*, argues that any ethnic group concerned with upholding or protecting their identity is also likely to attempt to control and define group purity through the use of beliefs about pollution.

The application of Douglas's (1966) conceptual themes to the findings in this research contextualised the prevalence of the respondents



describing the dangers, threats and risks associated with accessing certain services. The carers in the study regularly spoke about their positive perceptions of health and medical services. Respondents praised the availability of free national healthcare, and rarely made suggestions for how their needs could be more adequately met. Consequently, these accounts strongly contrasted with perceptions of and negotiations with social services. Here, respondents regularly argued that social services were ritually unclean, 'risky', dangerous, and threatened the purity of their cared for relatives. These pollution beliefs were informed by Judith Okely's (1983) classic work on the Traveller-Gypsies.

As discussed in Chapter Two, Okely's (1983) anthropological work on the Traveller-Gypsies provides an important contribution to understanding how minority communities in Britain uphold a sense of ethnic difference, whilst residing within mainstream society. She argued that the Gypsies in her study employed pollution beliefs about non-Gypsies (*Gorgios*), which served to reinforce and uphold symbolic boundaries between the Gypsies and mainstream society. Symbolic boundaries demarcated the space between the dangerous 'outside', or *Gorgio* territory, and the purity of the 'inside', or Gypsy territory. In this way, close maintenance of these boundaries served to resist assimilation into the values of mainstream British society. These contributions provide an important contextual framework for

understanding how the carers in the study reported negotiating access to social services.

Social services reflect the values of mainstream secular society, whereby facilities often provide only mixed sex services, non-*Halal* food and wipe rather than ritualistically wash cared for relatives after going to the toilet (*istinja*). In this way, respondents argued that social services are often incongruous with upholding Muslim religious and cultural values. As such, carers described how they managed their cared for relatives' experiences of services and often prevented access altogether. Incursions into such services often resulted in additional duties of care for the respondent. By ritualistically bathing a relative on their return (*istinja*) and packing *Halal* meals for their consumption at a social service, respondents were able to retain the purity of the cared for relative and uphold their Muslim religious identities. However, the importance placed on preventing females from mixing with the opposite sex (*purdah*) often resulted in carers perceiving mixed sex facilities as particularly dangerous as it threatened polluting the honour and respectability (*izzat*) of both the cared for relative and her family.

The Muslim notion of *izzat* (honour or self-respect) has been widely examined by scholars of Islam (e.g. Brown, 2006; Cooke, 2007; Ramji, 2007). Hussain (2005) provides the interesting link between *izzat* and disability, arguing that '[f]or disabled South Asian women their communities' views about disability add a further layer of complexity

around izzat' (p. 526). These arguments were strongly reflected in my research, where girls with learning disabilities were perceived as being particularly vulnerable to being corrupted or polluted by British secular values, subsequently threatening the purity of their reputation and the honour of the family (*izzat*). Consequently, the majority of carers of girls with learning disabilities did not access any form of social service outside of the home. Lynch (2007) conceptualises a 'care map' that is carried by the carer at all times, and through which routines of care are mediated and managed. The Muslim family carers in this research were also often required to manage an additional aspect of the care map pertaining to the behaviour and reputation of the cared for relative, especially if the chronically ill or disabled family member was female.

Harvey (2001: xi) argues that '[f]amilies who are part of a minority group within a dominant culture use various ways of maintaining their differences [...] families use the values of their religion to help define them and keep their subculture alive'. Similarly, Hunt (2002) argues that demarcating religious differences of an ethnic group within wider society increases internal solidarity, even where it was not particularly strong beforehand. As such, it is important to understand that services may be actively avoided in an attempt to demarcate and reinforce the symbolic boundary between the 'outside' (secular British society), and the 'inside' (traditional Muslim beliefs and values). In this way, services need to work with Muslim families on their terms. As Jaya, the manager of Organisation D argued '[i]t's got to fit, the glove has got to fit for them to

feel comfortable to go, and those services are not available'. These findings make an original contribution to knowledge pertaining to the experiences of Muslim family carers accessing state services. As Ahmed and Rees Jones (2008) suggest:

Previous studies of informal carers in ethnic minority groups have focused on lack of knowledge, information and language difficulties associated with poor access to services. This tends to lead to the view that what is required is more translation services, better transmission of information on entitlements and culturally sensitive services [...] we suggest that where there is evidence of lack of agency and resistance to support services, the explanation needs to move beyond poor information and language issues to accommodate a more rounded understanding of relationship between habitus and conflicts over local fields of welfare (p. 73).

These perspectives push the boundary of previous arguments, and acknowledge the importance of the nuances that exist within and between social groups in order to fully comprehend how uptake of services are accessed, perceived and experienced.

### **7.2.3 SOCIAL CAPITAL: THE FAMILY, GENDER AND CARING**

In the introduction to Allan's (1999) edited book *The Sociology of the Family*, he reflects on how the family structure has changed and developed within contemporary British society. He argues 'there is now far more diversity in the household and family patterns people construct

than there was during the first three-quarters of the twentieth century' (p.4). Similarly, Robertson Elliot (1996) argues that academic analysis of the family has been required to shift in complex ways, as ethnic differentiations within Britain has brought with it a new recognition of 'contradictions, tensions and diversity among women and men of different social groups' (p.2). This thesis adds to sociological debates surrounding the family by providing a unique insight into the dynamics of providing care within Muslim families. This is explored in more detail below.

Early scholars of care, such as Lewis and Meredith (1988) and Finch and Mason (1993) examined the ways in which responsibilities of care were negotiated within the family. They explored a 'hierarchy of care' to explain why certain relatives, especially women, undertake more care than other family members. A hierarchy of care was also observed within this research, whereby the responsibilities of care and the support for a carer was ultimately undertaken by women, even where men claimed to be the carer. Gendered perceptions about the obligations of women to provide care, was often mediated by the carers through a religious lens, whereby Islamic cultural practices and the *Qur'an* were regularly cited as dictating that women are the appropriate providers of care, especially in intimate tasks such as changing nappies, or using the toilet.

An additional division of care labour between women was also

observed. Traditional Muslim cultural practices of a new bride moving into the family home of her husband (Dhami and Sheikh, 2000) seemed to carry with it the expectation of providing care, or supporting a carer. The respondents regularly cited daughters-in-law and sisters-in-law as undertaking significant amounts of care work, again, even where others in the family cited themselves as the main carer. This research provides an interesting addition to knowledge about how responsibilities of care are negotiated within Muslim families.

It is also important to acknowledge how traditional cultural expectations of performing care solely within the home prevail, however, existing literature suggests that structural changes within the family may mean that certain forms of support that classically accompanied these expectations have declined. Ansari (2004) points to the continued significance of the family for Muslims in Britain, but also to the ways in which it has changed as a response to the dominant cultural climate (see also Ahmed and Rees Jones, 2008). The combined effects of women entering the labour market, getting married later in life, and subsequently having children at an older age has an impact on the number of relatives available within the domestic sphere to support and contribute to the care of a chronically ill or disabled relative. These changes were reflected within this study, where carers often expressed concerns about the care of a disabled child after their death. In contrast with Davys and Haigh's (2007) findings, whereby parents were worried about the strain on the siblings of a child with disabilities after their

death, the participants in this research expressed concerns that the influence of secular British values would prevent siblings from taking on their Muslim duty of care for family members. As such, this thesis identified a further contribution to the sociology of the family, principally pertaining to how responsibilities are negotiated within Muslim families.

This thesis is also valuable when viewed in terms of its contribution to social capital debates. As discussed in Chapter Two, the concept of social capital has become an increasingly important framework for understanding families, ties and kinship groups, and provided an interesting conceptual theme within this research. Proponents of social capital have classically been concerned with making grand narratives about how civic trust and reciprocity contribute to a social capital rich society and ultimately social cohesion (Choeng *et al.*, 2007). However, recent contributors to this debate have increasingly argued that such theoretical contributions homogenise the diversity of experience within and between groups. As such, empirical work in this area has made important developments to our understanding of how social capital is distributed within and between social groups and networks.

Zontini's (2010) work significantly contributes to this body of knowledge. She employs social capital to explore the complexities surrounding family ties and networks for Italian migrants living in the UK and Italy. Her research reveals that the family can be 'sources of satisfaction, resources and benefits, but also of sorrow, tension and frustrations' (p.

829). The findings in my study provide further support to these arguments. Whilst many respondents reported having transnational ties to family in other countries, which could be isolating at times, the family remained an important source of support. In support of Finch's (2007) conceptual arguments about the construction of the family, the family for the respondents in this study was adaptable, fluid and maintained the ability to provide support across national boundaries. As such, carers belonged to dense family networks, and successfully received support from family within the same household, within the same geographical location and from family in different countries. Therefore, this thesis adds to a growing body of literature that challenges common assumptions that migration necessarily reduces social capital.

This research also contributes to a growing body of knowledge that has both challenged and developed Putnam's (2000) bridging and bonding social capital distinctions. As articulated in Chapter Two, Anthias (2007) questions the usefulness of denoting a fixed boundary between bridging social capital and bonding social capital in that it risks essentialising the experiences within and between social groups. In her illuminating paper on social capital and the mobilisability of ethnic ties, Anthias (2007) argues that resources may only be usefully described as social capital if they are mobilisable for the pursuit of advantage, or the mitigation of disadvantage. Consequently, she asserts that the intersection of social factors such as gender, economic class, authority, age, and the ability to be recognised as a 'good' ethnic subject shapes one's ability to



access resources within and between groups. Leonard's (2004) empirical work on bonding and bridging in Belfast provides important context to these arguments. She asserts that moving from bonding to bridging social capital within certain groups may be beset with contradictions. The findings from her study suggested that bonding social capital may be obtained from a wider distrust of society. As such, she argues that making the transition from bonding to bridging social capital does not necessarily result in the positive outcome envisaged by Putnam.

My research provides an important addition to these debates in two ways. Firstly, it reveals how accessing support for care from outside of the group, or bridging social capital, often contradicts Muslim religious and cultural expectations of how care should be provided within the family, echoing Leonards (2004) arguments and adding a further layer of knowledge pertaining to the complexity of the bonding / bridging distinction. Secondly, it highlights how the mediating or 'bridging' presence of a Muslim carers' organisation can successfully access Muslim family carers by blurring the boundary between bridging and bonding social capital. Respondents in the study who were accessed through their membership to a carers' organisation were united in their accounts of how it positively supported them within their caring role. This was primarily due to recognition of the complexity surrounding Muslim family carers' access to formal support.

Organisations supported the carers by transcending the boundary of professional/personal relationships. As Hepworth (2003; 2005) acknowledges, the concept of 'friendship' is important to some South Asian carers in their relationship with professionals, and was a salient theme within this research. In this way, the informality of the organisation blurred the lines between receiving support from 'outside' the group (bridging social capital), and receiving support from 'friends' (bonding social capital). Relaxed meals, pampering sessions, 'bring-and-buy' sales, and craft competitions served a double purpose. Whilst providing respite for the carer within a religiously and culturally appropriate space, it also built trust, whereby the organisation was subsequently able to access cared for relatives for activities. This is a particularly important achievement, as many cared for relatives were often prevented from accessing social services outside the home.

#### **7.2.4 POTENTIAL CONTRIBUTIONS TO POLICY DEVELOPMENT AND SERVICE PROVISION**

This study is also valuable when viewed within the context of policy development and service provision. The Office for Disability Issues published the paper *Producing Better Information for Disabled People* (2008), which argues for better communication of health and social services for disabled people. This is an important provision for minority ethnic communities; however, I argue that carers need to be an integral part of this process, especially within the Muslim community, whereby the family is often central to how services are accessed. Service

providers need to be given the resources to work with carers within the diverse circumstances that are presented to them. Moreover, professionals working with Muslim carers and their chronically ill or disabled relatives need to be aware of the diverse religious and cultural obligations and expectations, especially surrounding the provision of care, gender (*purdah*), food (*Halal*), and washing after going to the toilet (*istinja*).

### **7.3 RECOMMENDATIONS FOR FURTHER RESEARCH**

Muslim family carers continue to remain an under researched group. Findings from this study indicate that further research is needed if we are to understand in more depth how care is perceived, performed and negotiated within Muslim families. Ahmed (2000) argues that as the number of Muslim citizens in the western world continues to rise, there is an increased need to understand the meanings attributed to illness and disability. These arguments need extending to the many Muslim individuals and families who care for those with illness or disability. Not only are carers too regularly overlooked within clinical practice (Lewis and Meredith, 1988; Phillips, 2007; Twigg and Atkin, 1994), the importance of Muslim family carers continues to be underplayed within academic literature. As such, this section makes five suggestions for further research and how such studies could contribute to existing knowledge. These suggestions include repeating this research; testing the findings using quantitative research techniques; exploring Muslim

perceptions of illness and disability in the family; exploring the domestic division of labour within Muslim families, and a comparative study of state service professionals and Muslim family carers.

### **7.3.1 EXPANDING THIS RESEARCH**

As research specifically focusing on Muslim family carers is particularly rare within academic literature, I suggest that this research should be repeated to further test the findings. Furthermore, the limitations that I acknowledge within this study could be addressed to strengthen the methodological approach to the data collection. This may be attended to in the following ways. Firstly, a larger sample size could make the findings more representative of Muslim family carers in Britain.

Secondly, using both an ethnically matched interviewer in addition to an ethnically different interviewer could provide a broader dataset, as it is acknowledged within the literature that this may have an impact on the findings (Archer, 2002; Elam and Fenton, 2003). Finally, accessing a wider spread of respondents in terms of gender, types of care provided, and participants that are both supported and not supported by a carers' organisation, would provide a fuller understanding of Muslim family carers in Britain.

### **7.3.2 TESTING THE RESEARCH FINDINGS USING QUANTITATIVE METHODS**

My research suggested that Muslim family carers of chronically ill or disabled relatives may experience their circumstances in interesting and distinctive ways. Furthermore, the findings indicated that there was a diverseness of experience between the respondents, which depended upon a range of factors including gender, economic class, and the ability to be accepted as a 'good' Muslim subject. I suggest that implementing a quantitative research method could interestingly test these findings. For example, a survey could test the qualitative research findings in this study more broadly. Perhaps the findings from this analysis could inform further qualitative research in this area.

### **7.3.3 EXPLORING MUSLIM PERCEPTIONS OF ILLNESS AND DISABILITY WITHIN THE FAMILY**

Sharma (1973) contributed an important addition to knowledge in her study of theodicy in a Hindu village. Evidence from an ethnographic study supported her argument that religious beliefs about misfortune and suffering are not necessarily constructed according to religious scriptures. The findings in this research provided additional strength to Sharma's arguments. For the Muslim family carers in this research, beliefs about misfortune and suffering seemed to be constructed within the situational circumstances of each social actor. An interesting addition to this research would be to examine and compare both the theodicies of individuals affected by illness and disability (such as

Muslims with disabilities, and their families), with a control group of Muslim respondents who are not affected by illness and disability. This study would provide an interesting comparative research project for exploring how the construction of religious theodicies intersects with situational factors of everyday life.

#### **7.3.4 EXPLORING THE DOMESTIC DIVISION OF LABOUR WITHIN MUSLIM FAMILIES**

The negotiation of domestic responsibilities within the family has played a central role in much feminist discourse surrounding the unequal division of household tasks (e.g. Oakley, 1974; Sullivan, 2000). The findings presented in Chapter Six adhered to this existing literature, whereby the allocation of care within the family seemed to be fundamentally divided along gender lines, with women undertaking the majority of care labour. A further possible division of labour was also observed between women. Here, women married into the family (i.e. daughters-in-law; sisters-in-law) were regularly cited as performing significant amounts of care work.

The relationship between female in-laws has been mapped by some researchers (Cotterill, 1994; Henz, 2009; Kim *et al.*, 2002), and their findings present some interesting conclusions pertaining to the distinct relationship between these relatives. Dhami and Sheikh (2000) observe the cultural practice within many Muslim families of a new bride moving in with the family of her husband, which was also observed in my

research. The role of these women within the family, however, remains largely unaddressed within academic literature. I perceive this relationship to be a worthy area of further research, especially in terms of how the allocation of domestic tasks is divided within Muslim families.

#### **7.3.5 COMPARATIVE STUDY OF STATE SERVICE PROFESSIONALS AND MUSLIM FAMILY CARERS**

By including the voices of fifteen professionals, whose occupation specifically related to supporting Muslim family carers, this study was able to gain an outside perspective of the relationship between Muslim family carers and their access to health and social services. Within this research, this was to specifically understand the role of the Muslim carers' organisation. However, further research comparing the responses of state service professionals with Muslim family carers may gain a broader perspective of how services are successfully accessed and the institutional barriers that can prevent access.

#### **7.4 CLOSING THOUGHTS**

This research project was originally undertaken with a set of preconceptions about how Muslim family carers would experience their everyday lives. The continuing negative spotlight on Muslim affairs has undoubtedly placed pressure on Muslim communities in Britain (Abbas, 2005), which has led to increased concerns about racism and Islamophobia (Ahmed, 2003; The Runnymede Trust, 1997). My

interpretation of these issues, combined with existing sociological literature mapping the barriers that immigrant communities (and in particular South Asian carers) experience when accessing health and social services, ultimately led to a set of preconceptions about how Muslim family carers would experience their everyday lives. In this way, I assumed that my respondents would present detailed accounts of negative encounters with health and social services, which would pertain to religious misunderstandings, cultural insensitivities, language barriers, and ultimately racism.

These preconceptions were outlined in Chapter One as a means of locating the original inspiration for the study, and as a way of mapping how these perspectives changed, as the findings revealed a much more diverse dataset than I had originally anticipated. Although many carers spoke negatively about their encounters of health and medical services, this was usually in reference to misdiagnosis and disorganisation at an institutional level, all issues that they considered had no link to their identities as Muslims. For example, Hakim, who cares for his adult son and daughter complained about the offhand way in which he was treated by a doctor at the local hospital when his son was admitted with a bladder infection, however, he reasoned that 'there are always a few bad apples in a box, but most of them are fine, you just have to throw out the bad apples'. Similarly, Meena, who cares for her son with severe physical and learning disabilities, argued that her GP did not



listen to her but she considered this to be due to service providers not being trained to listen to anyone, regardless of religion or ethnicity.

Most importantly, the respondents presented a diverse range of accounts that revealed how Muslim family carers are not a homogenous group, their experiences are based on a wide range of complex, interesting and intricate factors, beliefs and perceptions. It is only by examining these issues from the perspective of Muslim family carers that we can begin to explore how salient factors such as religious belief, culture, expectation, the family, and gender intersect and combine in complex ways which shape experiences of care.

# APPENDICES

## APPENDIX 01: GLOSSARY OF ISLAMIC TERMS

This glossary is included as an aid to explain some of the Arabic and Islamic terms that are used in this thesis. It is not designed to be exhaustive and predominantly presents the terms that are used either by the scholars that I have cited, or by the respondents in the study.

<i>Allah**</i>	Arabic for God
<i>Eid*</i>	Feast Marking the end of Ramadan (the Muslim month of fasting)
Hadith*	Traditions of the Prophet Muhammed
<i>hajj*</i>	pilgrimage, annually to Mecca and Medina
Medina	City in Saudi Arabia and second holiest place in Islam. Also burial site of Prophet Muhammad

<i>halal</i> *	permitted or sanctioned within Islam  (often used in reference to food and drink)
<i>haram</i> *	prohibited or unsanctioned within
<i>haya</i> *	modesty
<i>henna</i>	flowering plant used to dye skin, hair, fingernails, leather, and wool
<i>hijab</i> *	headscarf
<i>imam</i> *	religious leader, one who leads prayers in the Mosque
Islam**	The name of the religion preached by Muhammad, so named in the <i>Qur'an</i> , literally meaning “submission”; those who adhere to Islam are called Muslims
<i>Istinja</i>	Ritualistic washing after going to the toilet

<i>izzat</i> *	honour
<i>jinn</i> **	genies, another dimension of animate creation on earth
<i>kalimas</i>	Six principles of Islam, compiled from various Muslim texts to form the fundamentals of Islam. Compiled together to assist memorisation
<i>Madrassa</i> *	religious school
Mecca	A city in Saudi Arabia, considered to be the holiest meeting place in Islam
Mosque	Place of worship for followers of Islam
Muhammad	The founder of Islam, and considered by Muslims to be a messenger and prophet of <i>Allah</i>
Muslim**	A person who follows the Islamic religion

<i>Namaaz</i>	Shares meaning with <i>salat</i> , and refers to prescribed five daily prayers
<i>naat**</i>	devotional poem
<i>purdah*</i>	female seclusion
<i>Qur'an**</i>	Islam's Holy Book revealed to the Prophet Muhammad
<i>Ramadan*</i>	Muslim month of fasting
<i>salam*</i>	praising Muhammad by Barelwis
<i>salat**</i>	the prescribed five prayers a day, one of the "Five Pillars" required of all Muslims (also known as <i>Namaaz</i> )
<i>sira</i>	biographies of the prophet Muhammad
<i>shahada**</i>	"witness to faith"; saying (in Arabic), "There is no god but God and Muhammad is His messenger", one of the "Five Pillars" required of all

	Muslims, indicating conversion to Islam but also part of the ritual prayer ( <i>salat</i> or <i>namaaz</i> )
<i>shari'ah</i> **	Islamic laws
<i>surah</i> **	a chapter of the <i>Qur'an</i>
<i>umma</i> *	world-wide community of Muslims
<i>umra</i> **	the “visitation” of the holy places in Mecca, the lesser pilgrimage; it can be performed at any time of the year but it is also joined with the <i>hajj</i>
<i>zakat</i> **	alms tax, one of the “Five Pillars required of all Muslims (see Appendix one for description of the Five Pillars of Islam)

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\* Explanation of terms originally in Ansari (2004).

\*\* Explanation of terms originally in Rippin (2001).

## APPENDIX 02: THE FIVE PILLARS OF ISLAM

The basic duties of each Muslim are known as the Five Pillars and are briefly described below.

1. *Shahada*: the declaration of faith according to the formula (Ruthven, 1997). Muslims profess that there is no God but God, and that Muhammad is the messenger of God.
2. *Salat*: worship /prayer. This includes both the ritual of bodily movement as well as mental devotion to prayer. Sunni Muslims are required to perform *Salat* five times a day, at dawn, noon, mid-afternoon, sunset and evening. *Salat* can be performed virtually anywhere as long as the worshipper faces in the direction of the Ka'ba in *Makka* (Mecca).
3. *Zakat*: alms /compulsory charity. This tax can take the form of capital (2.5% of annual earnings), livestock, precious metals and merchandise used in trade (but not personal items such as clothing or jewellery). The recipients should be the poor and needy.
4. *Sawm*: the fast during Ramadan, which takes place during the holy month between the hours of sunrise and sunset and applies to restraint of eating, drinking, smoking and sexual activity.
5. *Hajj*: pilgrimage to *Makka* (Mecca), required of each adult Muslim at least once during her or his lifetime.

## **APPENDIX 03: INITIAL LETTER OF CONTACT**



School of Sociology and Social Policy,

University Park,

University of Nottingham,

Nottingham,

NG7 2RD

Tel: 07738389699

Email: [lqxsknb@nottingham.ac.uk](mailto:lqxsknb@nottingham.ac.uk)

[Name of organisation],

[Address of organisation]

May 17<sup>th</sup> 2006

Dear [insert name]

I would like the opportunity to meet you and learn more about your organisation. I am a PhD researcher at the University of Nottingham currently undertaking some research involving Muslim family carers of relatives with a chronic illness or disability. I am particularly interested in the ways in which Muslim family carers interact with and view the health care system. I am also interested in the ways in which Muslim family carers use their faith to come terms with and cope with chronic illness or disability within the family. Consequently, I



would like to interview Muslim family carers about their perceptions and experiences of being a carer of a chronically ill or disabled family member. The research is funded by the University of Nottingham and is supervised by Dr. Alan Aldridge and Dr. Alison Edgley. The project aims to provide a valuable insight into the lives of Muslim family carers.

I would like the opportunity to discuss with you the viability of my research ideas, and I would value your suggestions about how I might approach carers. I am aware that the subject area is sensitive and your organisation's expertise would be of considerable assistance to me.

I understand that you have drop in sessions and I would like to find out when these are, so I might come to [name or place of organisation] and meet you. I will contact you by telephone within the next two weeks.

Yours faithfully,

Sarah Buckman BA (Hons), MA

## **APPENDIX 04: INITIAL CONSENT FORM**



**University of Nottingham, Centre for Social Research in Health and  
Health Care**

Title of Project: Muslim Perceptions of Illness and Disability in the Family

Name of Investigator: Sarah Buckman

### Consent Form

Please read this form and sign it once the above named has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with the above investigator on all aspects of the study and have understood the advice and information given as a result.
- I authorise the investigator to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be

made anonymous. Data will be kept for 7 years after the results of this study have been published.

- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.

**Name:** .....

**Address:** .....

**Telephone number:** .....

**Signature:** ..... **Date:** .....

I confirm that I have fully explained the purpose of the study and what is involved to:

.....

I have given the above named a copy of this form together with the information sheet.

**Signature of Researcher :** ..... **Name:** .....

**Study Volunteer Number:** .....

## **APPENDIX 05: INFORMATION SHEET DISTRIBUTED ON INITIAL CONTACT WITH A CARERS' ORGANISATION**



### **Researching Muslim Family Carers**

**Sarah Buckman**

**Centre for Social Research in Health and Health Care**

Although there has been a wealth of research carried out on the needs of individuals caring for a chronically ill or disabled family member, and on the experiences of being Muslim in Britain, very little attention has been given to hearing the view, opinions and experiences of being a Muslim family carer in Britain. I have decided to dedicate my PhD thesis to this academic pursuit. As such, I wish to explore:

- The religious beliefs of Muslim family carers.
- The daily routines of undertaking care, including accessing health and social services.
- The kinds of support a Muslim family carer receives for their caring role, for example, from family members, the community and from carer groups.

I am interested in talking to both Muslim family carers and professionals who work with Muslim family carers. This could include carer group leaders, support workers, social workers, Imams, hospital chaplains, paid carers and government workers.

The conversations are anonymous, confidential and take place individually. They should take about an hour but I am happy to accommodate your needs. Conversations are also tape recorded so that I can accurately present what is said.

Formal support, such as benefits are not affected by taking part in this study. I am only interested in your views, experiences, beliefs and opinions. As such, you do not need to answer any questions that I ask you, and you are free to leave at any point in the conversation.

Conversations can take place wherever you feel comfortable, either at [organisation name] or at you home at a time which is convenient to you.

The aim of this study is to raise awareness within academia of the importance of a focus on Muslim family carers. As such, this research is worthwhile for both Muslim family carers and professionals to be involved with.

## **APPENDIX 06: CARER / PROFESSIONAL PRE-INTERVIEW INFORMATION SHEET**



**University of Nottingham, Centre for Social Research in Health and  
Health Care  
Researching Muslim Family Carers  
Sarah Buckman**

Please read this before the tape is turned on.

- Before we start you should feel satisfied that you have been given a full explanation of the recorded conversation you are about to take part in and the rest of the study.
- Please feel free to ask questions and discuss the study at any point.
- Some of the things you say in this recorded conversation will be discussed in future publications and presentations, but not your name or any other identifying features. All identifying features about you will be taken out of any parts of this conversation I use in future publications.
- All recorded information will be kept in a locked drawer. This information will be kept for seven years after the final report has been completed.

- You do not need to answer any of questions that you are asked if you do not want to.
- You can stop the conversation or leave at any time without needing to give a reason.

Thank you for taking part!

Please keep this information sheet and contact me if you have any questions or worries.

My email address is:

[lxsknb@nottingham.ac.uk](mailto:lxsknb@nottingham.ac.uk)

My office telephone number is:

0115 951 4891

## **APPENDIX 07: INTERVIEW GUIDE FOR CARERS**

EXPLAIN THE INTERVIEW AND RESEARCH, READ AND THEN

GIVE THE RESPONDENT THE INFORMATION SHEET

### **A. EXPLORING THE UNDERTAKING OF CARE**

1. Who do you care for?
2. What is/are the name/s of the person/people you care for?
3. Can you describe a normal day caring for [name], from the time you get up to the time you go to bed?
4. Does your family live near to you?
5. What kind of help do you receive from your family?
6. What do you do for fun?

### **B. ACCESSING SERVICES**

7. What sort of experiences do you have of going to the doctors, hospitals, physiotherapy or any other form of medical service?
8. What are your opinions of these services?



9. What are your experiences of social services such as day care centres, play schemes and special needs schools?
10. What are your opinions of these services?
11. How well do you think these services cater for the religious and cultural needs of religious people?
12. How well do you think these services cater for Muslims?
13. Would you suggest any improvements? And if so, what?

### **C. QUESTIONS ABOUT RELIGION AND FAITH**

14. What does being Muslim mean to you?
15. Have you raised [name] to be a Muslim? / Is [name] Muslim?
16. What are the Muslim religious teachings about care, disability and illness?
17. How does knowing this make you feel?
18. What religious practices do you do?
19. In what ways do you think being Muslim support [name of cared for relative]?

### **D. SUPPORT NETWORKS**

20. What kind of support do you receive for your caring role?
21. In what ways do family and friends support you?
22. How does the Mosque or Imam support you?

23. How supportive do you find the Muslim community?
24. What do you think would provide you with more support?
25. What, if any suggestions would you make to improve the lives of Muslim family carers in Britain?
26. (If accessed through Muslim carers' organisation) Tell me about [name of organisation].
27. In what ways does [name of carers' organisation] support you?

### **CONCLUDING THE INTERVIEW**

28. Would you like to add anything that you think I might have missed, or you think would be of interest?

THANK YOU FOR TAKING PART, PLEASE FEEL FREE TO ASK ANY QUESTIONS.

## **APPENDIX 08: INTERVIEW GUIDE FOR PROFESSIONALS**

EXPLAIN THE INTERVIEW AND RESEARCH, READ AND THEN  
GIVE THE RESPONDENT THE INFORMATION SHEET

### **A. PROFESSIONAL OCCUPATION**

1. Can you describe your professional role?
2. What's a typical day in your job?
3. What are the best and worst aspects of your job?
4. How often do you come into contact with Muslim family carers in your job? / In what ways does your professional role support Muslim family carers?
5. To what extent would you say that your job is a part of your identity?
6. What do you think carers do to relax?

### **B. ACCESSING SERVICES**

7. What are your opinions of health and social services in terms of their ability to cater for the needs of minority religious groups?
8. What are your opinions of health and social services in terms of their ability to cater for the needs of Muslim family carers?
9. Would you suggest any improvements? If so, what?

### **C. RELIGIOUS BELIEFS**

10. In your opinion is there anything unique about the undertaking of care in a Muslim family.
11. What do you perceive to be the Muslim or *Qur'anic* teachings of care, illness and disability?
12. How important is religious belief for Muslim family carers?

### **D. SOCIAL NETWORKS**

13. How important is the family for supporting Muslim family carers?
14. What is the role of the local Mosque or Imam within the community? In what ways does the Mosque or Imam support a Muslim family carer?
15. How important is the role of the Muslim community for Muslim family carers?

### **CONCLUDING THE INTERVIEW**

15. Would you like to add anything that you think I might have missed, or you think would be of interest?

THANK YOU FOR TAKING PART, PLEASE FEEL FREE TO ASK ANY QUESTIONS.

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