Habitus and Bureaucratic Routines’, Cultural and Structural Factors in the Experience of Informal Care: A Qualitative Study of Bangladeshi Women Living in London
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abstract: This article draws on Bourdieu’s notion of habitus to address the interaction between cultural and structural factors in influencing the experience of informal care among Bangladeshi women in London. The authors present a secondary analysis of a qualitative study focusing on the accounts of informal care. The data were drawn from a two-year study with Bangladeshi women aged 35–55. Thirty-two out of the 100 women in the original study were providing care, mostly in isolated circumstances and with little or no formal support. The authors analysed the accounts of these 32 women and in the context of high levels of suffering and distress, three key themes emerged: amplification of suffering, dispositions of duty and religion and entitlements and fields of struggle. The gaps in access to formal support faced by these women suggest that strong cultural and structural forces determined their experience of informal care and the meanings they attached to their role as informal carers. Drawing on the work of Bourdieu and others, the authors suggest that where there is a lack of agency and resistance to support services, the explanation needs to move beyond poor information and language issues to a more rounded understanding of relationship between habitus and conflicts over local fields of welfare.

keywords: Bangladeshi women ✦ ethnic minorities ✦ habitus ✦ informal care ✦ London
Introduction

Research on informal care among minority ethnic groups in the UK is limited (Merrell et al., 2006). Little is known about levels of caring among black and minority ethnic groups. There is some evidence to suggest that with respect to caring for other adults at least, there are similar levels of caring among ethnic minority groups compared with whites but the experience of caring may be modified by specific issues (Karlsen and Blanchard, 2002). These include racism, poor communication and culturally insensitive services (Katbamna et al., 2002). Studies have also shown that while the role of informal carer is often accepted by South Asians their acceptance is accompanied by a sense of disruption affecting their role within the family and also affecting key relationships (Adamson and Donovan, 2005). Informal carers within minority ethnic communities are at greater risk of being disadvantaged and becoming socially isolated and this has been related to assumptions made by health and social care providers about their community and culture (Atkin and Rollings, 1992; Katbamna et al., 2004). Comparative studies have shown that there are ethnic differences in the impact of caring responsibilities on the lives of informal carers. For example, black Caribbeans report more restrictions on their daily lives than white carers (Koffman and Higginson, 2003). Little is known about the relationship between structural and cultural factors in the provision of informal care and how these influence the meanings attributed to the experience of informal care. There may be particular aspects of informal care in migrant communities that are being neglected. For example, the gendered features of informal care, the impact of informal caregiving across generational groups, tensions and conflicts that arise within and between family groups and the impact of organizational and structural factors on access to material and emotional support. This article draws on Bourdieu’s notion of habitus (Bourdieu, 1990, 2005) to address the interaction between cultural and structural factors in influencing the experience of informal care among Bangladeshi women in London.

Background

Informal Care, Welfare and Social Support

In the UK, there is evidence to suggest that there are low levels of knowledge and willingness to draw on welfare services and entitlements among the general population. It has been estimated that around 1 million state retirement pensioners do not claim means-tested pension benefits (Acheson, 1998). Uptake of services and entitlements among informal carers is therefore an important policy question, and the relative position of
black and minority ethnic groups a key component of policy concerns. A study of the views of Bangladeshi carers in South Wales (Merrell et al., 2006) found some evidence of inequity of service provision and that uptake of services was impeded by barriers that included scarcity of time, resource constraints, language barriers and no staff from the same ethnic group in welfare offices. Low levels of awareness of social services have been previously found among older black and minority ethnic groups (Murray and Brown, 1998), and among Bangladeshi carers at least, these appear to be accompanied by resistance to taking up some services where they are known about (Merrell et al., 2005). Other studies have identified that older South Asian people have limited knowledge of social services and welfare benefits (Bowes and Dar, 2000; Bowes and MacDonald, 2000). Johnson et al. (2000) identified low levels of literacy among older Bangladeshi women and a consequent reliance on children for translating. Language difficulties can also have a detrimental impact on the quality and experience of formal care (Gerrish, 2001). Gaps in knowledge, however, cannot always be explained by language difficulties (Vernon, 2000). Attempts to overcome barriers to service provision have included encouraging information routes through ‘word of mouth’ (Murray and Brown, 1998) and the use of videos and audio tapes with varying levels of success.

It is not surprising, therefore, that health and social care in the community is perceived to be problematic for minority ethnic groups. For example, community support services are often underused by minority ethnic older people (Blakemore, 2000; Sonuga-Barke and Mistry, 2000) and policy and services are sometimes insensitive to the needs of minority ethnic communities (Atkin and Ahmad, 2000; Katbamna et al., 2002). Myths and assumptions about South Asian families still prevail and stereotypes about the extended family and the availability of intergenerational support have been shown to inform policy and practice (Qureshi et al., 2000). Researchers have shown how the concept of the extended family is poorly understood (Ahmad, 1996) and the view that South Asians ‘look after their own’ is common (Murray and Brown, 1998). This can sometimes have pernicious effects. For example, a study of mental health care and primary care professionals in the UK showed how the view that South Asian communities ‘look after their own’ informed professionals’ ideas about the aetiology of depression among South Asian women being rooted in family and cultural effects (Burr, 2002). Studies of social support and ethnicity have identified differences between ethnic groups but the evidence is ambivalent (Stansfeld and Sproston, 2002). Although social support is provided from a number of sources, in the main, studies on ethnicity and social support focus on family-based social support. Studies have shown that, compared to whites, Indian, Pakistani and Bangladeshi men and women and black Caribbean women see fewer friends and more relatives (Stansfeld and
Sproston, 2002) and stress the importance given to family life among ethnic groups with respect to health (Shams and Williams, 1995). Support from friends from the same ethnic group has also been emphasized (Modood et al., 1997; Stope-Roe and Cochrane, 1990), as has the importance of generation in understandings of social support and ethnicity (Guglani et al., 2000). Stansfeld and Sproston (2002) found that second-generation Pakistanis, Bangladeshis and black Caribbeans were more likely to report low levels of emotional support. However, simplistic ideas about support in families may obscure similarities across ethnic groups (Ahmad, 1996). Stereotypes of ‘the Asian extended family’ may lead to assumptions among service providers that the needs of minority ethnic elders are adequately cared for in the family setting (Blakemore, 2000). Indeed, criticisms of the research literature on ethnicity and health focus on the reliance on static notions of culture (Karlsen and Nazroo, 2000) that mask the importance of material circumstances to the detriment of more nuanced understandings of the interaction of structure and culture over time.

**Habitus and Understandings of Welfare**

The work of Pierre Bourdieu may offer one way of addressing these shortcomings. Although the term habitus can be traced back to the Ancient Greeks and was taken up by a number of sociologists in the 20th century, it is in the work of Bourdieu that it has been used most extensively as a mediating concept to address the duality of structure and agency. In Bourdieu’s hands, habitus captures the way the social is internalized individually; integrating all past experiences in the form of durable, lasting and transposable dispositions to think, feel and act. This informs Bourdieu’s notion of practice, which is a dialectical relationship between a given situation and a habitus (Bourdieu, 1977). Habitus varies across space and time and according to Bourdieu is transferable across various forms of practice, thus contributing to the development of distinctive class-based lifestyles (Bourdieu, 1984). However, habitus is not static and dispositions can be changed and reformed in response to social changes such as migration (Wacquant, 2004). This point is important to this present study in that the women interviewed may have brought with them to the UK sets of dispositions and practices based on their lives in Bangladesh and these in turn may have moulded and been moulded by the social milieu they encountered and constructed in the UK. Bourdieu also incorporated the concept of field into his work, which he interpreted as a site or sites for struggle and the unfolding of power games over a central stake. He refers to the resources used in these struggles as different forms of capital: economic, social and symbolic.

Attempts have been made to utilize Bourdieu’s concepts in a sociology of welfare. For example, Peillon (1998) has proposed a framework to
develop understandings of different welfare regimes and the interactions between welfare agencies and welfare recipients. Moffatt and Higgs (2007), in a qualitative study of older people in Northeast England, suggest there is a generational welfare habitus that underpins the non-uptake of state welfare benefits among older citizens. They postulate a mismatch between older citizens’ attitudes to and expectations of the state and the modernized welfare state’s view of citizen consumers. Drawing on Gilleard’s work (Gilleard, 2004), they argue that a generational field relates to the emergence of changed relationships between past and present social spaces, and generational habitus refers to dispositions emerging from a generational field that structures individual practices. They use this to explain the feelings of shame, stigma, pride and notions of charity that underpin the reluctance of older people to apply for benefits they are entitled to. They conclude that many older people hold a traditional view of welfare embedded in a generational habitus that draws on deeply held beliefs about rights, entitlements, duties and resistance to means testing. This potentially conflicts with ‘Third Way’ social policies that emphasize choice, individualism and citizen consumers. Finally, Bourdieu himself, in his later work, addresses the sociology of suffering and the social practices associated with housing regulation (Bourdieu, 1999, 2005). Although Bourdieu’s work has been justifiably criticized for placing too great an emphasis on traditional family forms in the production of legitimate dispositions (Silva, 2005) and for presenting a static account of working-class culture (Bennett, 2005), his later work is important because it provides a theoretical framework for understanding the ways in which individual citizens often lack the resources with which to ‘play the game’, to negotiate the labyrinthine rules of welfare and state bureaucracies. For many citizens/subjects falling within its jurisdiction, the state is in the form of regulations and the local agents applying those regulations, and Bourdieu exposes the ways in which some groups are better at tacit rules than others and are able to negotiate the duality of tacit and formal rules. Here also the work of De Certeau (1984) offers useful insights in that he distinguishes between two types of action or practice: strategies and tactics. The former type is usually a feature of institutions: recognized as having authority and dominant status with strength in terms of the resources that it entails. The latter type is usually a feature of individuals or groups: lacking a fixed position it is often makeshift but is the means through which individuals may subvert the strategies that institutions impose upon them.

In this article, we attempt to draw on these different notions of habitus, practice, field and ways of ‘playing the game’ to examine the ways in which the lives of Bangladeshi women were affected by providing informal care, their feelings towards and perceptions of providing informal care and their knowledge and interactions with health and social care services.
Methods

We undertook a secondary analysis of a qualitative data set focusing on accounts of informal care. Secondary analysis involves the utilization of existing data collected in prior studies. Secondary analysis of qualitative data can take numerous forms. These include: (1) using a different unit of analysis in the secondary analysis from that used in the primary study, (2) analysing a subset of cases, (3) focusing on a concept not specifically addressed in the primary analysis and (4) using a qualitative data set to refine and inform a study (Hinds et al., 1997). The analysis undertaken for this article focuses on a subsample of women providing care and focuses on a concept not specifically addressed in the primary analysis. The data were drawn from a two-year qualitative study conducted in Tower Hamlets, London between 2000 and 2001 with 100 Bangladeshi women aged 35–55, exploring the impact of migration on their lives (Phillipson et al., 2003). All women were interviewed in their homes at a time that was convenient for them; interviews lasted around an hour. Participants were recruited using GP lists. Seventeen health practices were invited to take part in the study, of which seven from around the borough agreed to take part. From the lists of Bangladeshi women aged 35–55 provided by the practices, a random selection of names was carried out and yielded a sample of 220 women to potentially invite to take part.

Recruitment to the study was a two-stage process. The first stage involved contacting the women by post. In order to increase chances of reaching those with literacy problems, the letters were sent out in Bengali and English; it was anticipated that if the women themselves were unable to read the correspondence their spouses or children might be able to convey the information to them. The letters contained brief information about the study and advised the women to expect a phone call from the researcher where they would be given further details. The information in the letter was kept brief in order to minimize the risk of overwhelming the individual.

The second stage of the recruitment involved phoning all those who had been written to, to answer any questions they had and arrange a time for the interview if they were happy to participate. At this stage of recruitment, it was found that 30 percent of the sample had the wrong details. After removing those with the wrong details from the sample and concentrating on only those who went through both stages of letter and phone call, the sample size reduced to 154 respondents. Of those, 65 percent (100 respondents) agreed to take part. Most interviews were arranged during the initial phone call to discuss the letter. However, in some cases, on the request of the respondent, a subsequent call was made to arrange a time to interview, e.g. if they were going away or the children were on holiday from school. Interviews took place usually within a few days. All respondents were
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phoned the day before as a reminder and to confirm they were still happy to take part. In addition, they were phoned half an hour before the scheduled interview to allow them to opt out if they chose. All interviews were conducted in the respondents’ homes at a time of their convenience. The respondents were asked to sign a consent form, available in English and Bengali. In most cases, due to low literacy the consent form was verbally administered and the respondent asked to sign. All respondents were given a copy of the form in English and Bengali to keep. The interviews looked at all aspects of the women’s lives in the context of migration, including their life prior to marriage and migration, relationship with family members, education, employment, etc. (see Phillipson et al. [2003] for the full interview schedule). Open-ended questions around informal care were presented, asking whether they cared for anyone and the nature of the care provided. They were also asked whether they felt they needed help with the care. The majority of interviews, and all interviews with carers, were conducted in Sylheti and later transcribed into English.

Of the 100 women interviewed, almost a third (32) were providing care, mostly in isolated circumstances and with little or no formal support. This article is based on a secondary analysis of these 32 interviews. The majority of women were caring for a spouse (16) while others were caring for a child with disabilities (eight) or elderly in-laws or parents (five); a further three women were providing care to more than one person – one was caring for her husband and a child, one for a child and father-in-law and the third for her husband and two children.

The carers sample has a greater number of women represented in the younger age bracket and 29 (more than 90 percent) had a family size of five or more children compared with 66 percent in the overall sample. Table 1 shows the age distribution of the carers subsample in comparison with the age distribution of the main sample.

The women were providing care within the specific location of Tower Hamlets. The London borough of Tower Hamlets is one of the most disadvantaged areas in the UK. There are high levels of deprivation in areas of health care, housing and employment across the borough. Tower Hamlets has a very large and diverse minority ethnic population, and people of

| Table 1 Comparison of Age Distribution of Carers Subsample with Main Sample |
|-----------------|---------------|-----------------|
| Age             | Main sample   | Carers subsample |
| 35–39           | 29            | 12              |
| 40–44           | 29            | 8               |
| 45–49           | 21            | 5               |
| 50–55           | 21            | 7               |
Bangladeshi origin make up the largest minority group in the borough. Bangladeshis are one of the most deprived ethnic groups in the UK. The first major wave of Bangladeshi settlers arrived during the 1950s and 1960s (Kershen, 1997). These were mainly male migrants who came with a view of temporary settlement but as time passed they settled for the long term, and sought to bring wives and families over from Bangladesh.

For the carers, caring duties centred on help with eating, dressing, mobility and administering medication. We reviewed the accounts the women gave of providing informal care and the data were then analysed according to key themes. Themes are presented using a mixture of illustrative quotes and extracts from case studies. The case studies relate to the interviews with two women, Fatema and Ferdousi. The accounts of these women were selected because they highlighted common themes in the struggles the women in our sample had over fields of welfare and care. Both case studies uncover the extent to which the women were vaguely aware of the possibility of entitlement to support but were also unsure of the formal and tacit rules that governed such support. They are also indicative of the extent to which material conditions and cultural expectations interact to constrain the women’s lives. The data are anonymized and all names mentioned in the extracts are pseudonyms.

**Results**

The demands of care provision affected the social, physical and emotional aspects of the lives of the carers. The women’s roles as carers often went unrecognized or unsupported by service providers. They were often unaware of services available to them or about appropriate benefits they were entitled to receive. The role of carer was commonly associated with a sense of duty that was linked to cultural and religious beliefs. Tensions across generational groups were apparent and the impact of caring on social isolation was profound. In the context of high levels of suffering and distress, three key themes emerged: amplification of suffering, dispositions of duty and religion and entitlements and fields of struggle.

**The Amplification of Suffering**

Within the Bangladeshi community, the primary carer is usually the female head of the house, unless she requires the care and then the role of carer tends to be devolved to the next female in line. One notable feature of this group of carers is that they often become involved in care at a comparatively young age, as the age for onset of disability in ethnic minority communities is on average younger than the general population (Atkin and Rollings, 1996). When their husbands became ill in their thirties and forties, women would become carers at their corresponding, usually younger, ages and
often have to be a full-time carer as well as bringing up young children. Inadequate housing is one of the main problems that compounds difficulties in providing care. Most of the respondents in this study lived in council tenements, often overcrowded high-rise flats. Twenty-two of the carers considered their homes to be overcrowded, and 18 lived in blocks with no lifts. Twenty of the 32 carers reported problems with damp in their homes and expressed their frustration at the council for its apparent indifference to their problems. Many had had to resort to financing repairs themselves, but more often than not the damp problem permeated the building so any internal cosmetic repairs were futile and had to be frequently repeated, thus it was a recurrent financial burden on them. There was a high level of dissatisfaction with housing conditions and many wanted to move to better housing, but seemed to accept that the possibility of rehousing was slim. Material disadvantage therefore contributed to the difficulties associated with informal care. In addition, a significant consequence of informal care was the increasing social isolation that accompanied caring. The women were rarely able to take any time out for themselves and when they did, they would worry about the person they were caring for. As one respondent said:

He can’t do anything for himself. When I go to college I put his meal in the microwave and set the timer so all he has to do is press start. I go at one and come back at three. In that time he prays and eats. He is always in a lot of pain, so I have to spend as much time with him as I can, in case he needs anything. I worry about him all the time. (Rohima, 43 years old, length of time in UK 18 years, caring for husband aged 55 with arthritis and kidney problems)

This respondent was able to carry on with going to college, but most women became increasingly housebound. Overall in the study, most of the women interviewed, regardless of whether they were caring or not, socialized only with their family and neighbours. Their days were focused around the home and family – dropping children at school, cooking, taking the children to after-school Arabic classes, housework, etc. Within that routine, there was seldom time to see friends; and when care duties were particularly onerous, they were almost entirely housebound, particularly given their role as sole carer:

I have to be with him all the time, I never leave him alone in the house. (Ranu, 49 years old, length of time in UK 16 years, caring for husband aged 65 with heart problems and severe asthma)

Providing care often in a cocoon of isolation led to feelings of frustration and anger, and some of the women revealed strong feelings of resentment towards those they cared for:

He needs help with doing everything. Bathing, dressing, toileting, feeding. If he goes to the bathroom he messes it up totally. He soils his clothes. He can’t go
out. Me and my sons do the shopping. I don’t know if I should say this about my own husband but he can be very demanding. He always wants things straight away. He always wants different things to eat and drink. If he asks for something and you get it, by the time you’ve got it he will have changed his mind and wants something else and starts shouting. (Fazira, 54 years old, length of time in UK 16 years, caring for husband aged 70 with diabetes)

It is possible to see these accounts in terms of sets of practices and dispositions interacting with structural constraints and having particular consequences for the women in the study. The expectations on the women to conform to a particular caring role within the family structure amplified the burden of informal care. Already an isolated group, the constant time and attention Bangladeshi women are required to give further isolates them from any friends or neighbours they may have. People tend to stay away for fear of ‘bothering’ the caregiver when she has so much to deal with, and thus serve to only compound the loneliness and distress. The literature suggests that female carers experience greater isolation than male carers and are also less likely to receive formal support than male carers (Bhalla and Blakemore, 1981). This group of Bangladeshi women appeared particularly prone to isolation as they lack language skills and had hitherto depended upon their spouses to take care of things. This isolation appeared to be related to the expectations surrounding the duties of a Bangladeshi woman to undertake care, which were not necessarily backed up by the traditional forms of social support that might have previously accompanied such expectations. Safia talks about the support received in caring for her husband in Bangladesh:

It is hard [in London] because we live on the fourth floor and there is no lift; because of that he can’t get out much. We were in Bangladesh and he was looked after by me, his brother and his family. But after his brother died my children brought us over. He [husband] liked it there because he said the warm weather made him feel better. (Safia, 53 years old, length of time in UK 32 years, caring for husband aged 75 with paralysis)

**Dispositions of Duty and Religion**

Most of the respondents expressed a strong sense of duty to provide the care. This sense of duty derived from strong religious (Islamic) beliefs and appeared to place constraints on seeking outside support. This was particularly the case when they were caring for someone who had become infirm due to old age. This kind of care creeps up on the individual and they gradually find themselves doing more and more, and often do not identify themselves as a carer and see themselves simply as a wife doing her duty. There was a sense of ‘duty’ about providing care. Most of the women in the study ascribed their position in life to be the will of God:
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I am coping, and as long as Allah keeps me alive I will take care of him. We don’t need any help. (Ranu, 49 years old, length of time in UK 16 years, caring for husband aged 65 with heart problems and severe asthma)

One respondent, who was a single parent caring for her son and grandson – one of whom had muscular dystrophy – as well as nine of her own children, said:

Social Services say, ‘If you can’t manage to look after them, then we will take them into care’. But as long as my eyes are open, I will never let them go into care. I will never let them go. (Rupa, 50 years old, length of time in UK 22 years, caring for son aged 11 with learning difficulties and grandson aged six with muscular dystrophy)

As suggested earlier, the existence of an extended family network does not necessarily mean the availability of a readily supportive network (Walker and Ahmad, 1994). There may be an idealized view of what one could expect in Bangladesh 20 years ago. In reality, many people do not have access to such support, for a variety of reasons. The constraints of housing mean that families are necessarily constricted in size, the housing may not comfortably accommodate additions to the core family unit. Changes in household structure and the geographical distribution of family members either through dependency on council accommodation or occupational mobility can render wider family members unable to be involved in care provision even when they have a sense of obligation. There are also generational effects. The older generation come from a tradition where children take care of their parents. If this does not happen in the UK, for whatever reasons, including geographical dispersal and occupational mobility, there is a sense of being let down.

While assumptions about informal care within extended families can lead to poor access to formal care, it may also be the case that traditional routes to securing informal support can clash with the welfare system’s modus operandi. For example, Sabina recounted her hopes for increased support in the home from her son’s marriage but found this inadvertently made the situation worse. She claims that the council encouraged her son to move out in order to help speed up their application for a larger home. Having done this, they are now left in the same home but without the support of her son and his wife:

I got my son married at a young age so that I would have someone else to help around the house. My health isn’t good either. . . . The council told my husband that they wouldn’t give us another house until we moved our son out. . . . So my son became homeless, and my husband went back to the housing office and they denied it . . . the whole reason I got my son married was so that they could be with us. (Sabina, 50 years old, length of time in UK 16 years, caring for husband aged 64 with Parkinson’s disease and son aged 17 with learning difficulties)
Many may feel too embarrassed to look for external help because it would be an indication to others in their family and social circles that somehow their own family had let traditional standards slip. These feelings of ambivalence towards outside help seemed particularly strong in those women who were caring for husbands or older male relatives:

They were going to give us a nurse to look after him at home, but he doesn’t want that – he can’t think properly, and he just says that he doesn’t want a nurse; he wants me to do everything. And we just want to do whatever keeps him happy, so we haven’t got a nurse. . . . They [nurses] tell me that it is too much for my health – but what can I do? If he doesn’t want anyone then I have to. It is in my fate to do all this. (Salma, 52 years old, length of time in UK 25 years, caring for husband aged 66 with heart and mental health problems)

It was not only the spouses who were uncomfortable with the idea of nurses, part of the rejection of outside help by the carers was the fact that it was precisely that – outside help. Not only was it tantamount to admission of failure to cope and fulfil their duties, but outsiders could not always be trusted with care. As Fazira says:

I won’t get any peace of heart if there is anyone else helping out. However much a stranger does it’s not the same as doing it yourself. My sons help me. (Fazira, 54 years old, length of time in UK 16 years, caring for husband aged 70 with diabetes)

Entitlement and Fields of Struggle
One of the strongest themes to emerge from the study was the extent to which the women were either unaware of the benefits they were entitled to (only three of the 32 carers were in receipt of carers’ allowance), but also confused about the means of obtaining support and the sources of support. To illustrate the complexity of this, we present two case studies, those of Fatema and Ferdousi. In each of these case studies, one becomes aware of the levels of material deprivation and the heavy burden of care on the women involved, the extent to which the women exist on the margin and how the smallest event can have profound repercussions in terms of their capacity to cope. Their habitus reflects a complex mix of their experience as Bangladeshi women and their ethnic and class location in the UK. For Fatema, there is a strong sense that she is trapped by her caring role but in her account one can discern that there are strategic and tactical aspects to this, reflected in the power games implicit in her husband’s response to ‘English’ as opposed to ‘Bengali’ community psychiatric nurses (CPNs) as well as a sense of helplessness in her own capacity to respond to the form filling requirements of the welfare system. Ferdousi’s very heavy caring burden is amplified by her housing circumstances but despite receiving benefits her account gives a strong impression of someone who has
attempted to follow the procedural requirements of the housing system but now lacks a clear response to the inaction or indifference of the system. In both cases, unequal power struggles are fought both in the home and in the welfare field and the women’s habitus may contribute to the development of dispositions that disadvantage them in both sites of struggle.

**Case Study 1: Fatema**

Her husband is mentally ill and she is his sole carer. She has two young girls and has recently found out that she may be eligible for support as a carer, and although she has managed to get a form is unable to fill in the form by herself. Her husband is always demanding money for cigarettes. The constant strain has caused her to have severe headaches; when she went to her GP she was told that it was due to the situation with her husband and her GP (much to her amusement and horror) advised her to leave her husband. Ideally she would like to do courses and learn to drive but she can’t leave her husband on his own for any length of time and when she is out she is worried about him burning the house down – he has a tendency to leave cigarettes burning and the gas on.

**Interviewer:** Tell me a little bit more about the care you provide for your husband.

**Fatema:** What can I tell you? He drives me mad! My husband is very ill. Everyone knows that he is ill. My whole day goes taking care of him and fitting everything around him. I have left him today, I am worried about whether he puts the cooker on, he’ll just leave the gas on without igniting the flame. I’m scared he’ll do that. He has a lot of problems.

**Interviewer:** Do you have any help with taking care of him?

**Fatema:** No I live on my own so I have to take care of him on my own too.

**Interviewer:** Have you contacted Social Services?

**Fatema:** I did once, but they don’t do anything. They’ve come a couple of times, but he doesn’t like it when anyone comes round. He doesn’t want anyone to know that he is ill. He just says that why should they come, he takes his medication so he is fine. But they do come around still; a CPN comes from time to time. It’s an English lady and she argues back at him and tells him off, but if a Bengali one comes he doesn’t like it, he threatens to throw them out!

**Interviewer:** How did you contact Social Services?

**Fatema:** I didn’t really contact them, my children were very young at the time and I had to go to the clinic all the time. I kept on missing appointments and they asked me why and I told them that I couldn’t come with two children on my own and my husband was ill. They said they would help us and then they sent someone for a while. Then my brother-in-law got married and his wife helped me out a lot, going to the doctor and hospital. Sometimes she would
just take him and I would be with the children and at other times she would look after the children and I would go with him.

. . . Do you know in this country, I didn’t know it, I don’t know if other people know, but if a wife looks after her husband then she can claim money. I look after him totally, I have for years, but I don’t get any benefits. The CPN told me the other day, so I went to the place she told me to, to get the form, and they told me to fill in the form and bring it back. I told them that I didn’t know how to fill in the form and they said to go to Bethnal Green or somewhere, to the One Stop Shop. How am I supposed to get there? It is too far for me to go. So I will have to get someone to fill it in for me. I don’t know if I will get any money or not, but if I can claim then I should. I suppose it depends on how well you can fill in the form.

Case Study 2: Ferdousi

The respondent is 43 years old and married with seven children. She has been living in the UK for 10 years and not yet returned to Bangladesh since her arrival. They have a six-year-old daughter who is disabled. She has sight and speech problems. She does go to a special school, but they do not know of any other support they could be receiving. Housing is a major problem. They live on the top floor of a block of flats with no lift. The flat is in a very dilapidated condition. With nine of them living in a three-bedroom flat they have to use the sitting room as another bedroom.

Interviewer: Could you describe the care you provide?
Ferdousi: She [daughter] is handicapped. She is blind and she can’t speak very much. She goes to a special school. The bus collects her every day. I have to get her ready and do everything for her. She is still wearing nappies because she can’t tell us when she needs to go to the toilet. I have to do everything for her, wash her, bathe her, feed her, dress her. Everything.

Interviewer: Do you feel that you need more help (for example, from local services) in providing this care?
Ferdousi: They are giving us a benefit. But they haven’t made any changes to the house. After she was born they said they would make it easier for her but they haven’t done anything. We applied for a transfer but they haven’t given us anything. We applied straight after she was born. We don’t know what help we can have. Some people have said that we should get more money for looking after her – I get £40 a week. But I don’t know where we could get help or what kind of help we could be getting.

One respondent, Kulsuma, had to provide full-time care to her 77-year-old brother-in-law. She did everything for him – he was practically bedridden.
She would feed him and have to clean up whenever he didn’t make it to the toilet, and when asked if she was getting any help, she said no, because she did not know how to. While the women in the study bore the majority of the caring duties inside the home, when it came to interacting with health providers they were often unable to take the lead primarily because of language issues. In such cases, other family members, usually children, were drafted in. The knock-on effect on children of unsupported care is often overlooked. Saleha, one of many respondents who relied heavily on her children, says:

They [her children] sometimes have to miss their school and college if they have to take them to the doctor or hospital appointment. . . . I did wish that if I could get someone, like a health visitor, or someone like that. . . . My children are older now, school is important for them. If you go to the hospital you will be waiting all day before you are seen. . . . I have told the doctor, but they don’t help. I have asked the doctor to help us arrange something for taking them to hospital and back, or to the surgery and back for appointments. If my children aren’t at home, how do we go? And I have to be at home because they all come home at different times from school and college. They need feeding at different times, letting them in, all of these things. But the doctor hasn’t helped us. They don’t say anything. (Saleha, 37 years old, length of time in UK 20 years, caring for elderly parents-in-law with diabetes and mobility problems)

Some women were clearly receiving high levels of support and it is significant that these were usually those who were looking after children. It may be that information and access to entitlements in this area are easier but it may also be that barriers to accepting support for childcare may be less acute. Sometimes it had been schools or hospitals that had alerted the women to the problems in the first place and that had been instrumental in organizing relevant support:

When he was three. He went to school, and he fell over in the playground. Then he kept on falling over and hurting himself. He would injure himself badly – hurt his arms, his legs, his teeth. The teacher made us take him to the doctor to see why he kept falling over. The doctor referred him to the hospital, where he had lots of tests done. They took some flesh from his thigh, and then told us it was muscular dystrophy. (Rupa, 50 years old, length of time in UK 21 years, caring for son aged 11 with learning difficulties and grandson aged six with muscular dystrophy)

But in some cases the support seemed rather ambivalent. This seemed to be particularly related to the perceived transient nature of key workers. It takes time to build up trust with a family, and it can be very disconcerting and confusing for a family when their key worker leaves. For some, their social worker was often the only contact to other services such as housing, welfare and special education that they had, and when that crucial link was broken they could feel stranded and let down:
He had a social worker who used to take him to a centre. But he has left. Before he left he said that he was passing my husband’s file onto someone else and they would come and see us. But no one has come. (Waheeda, 39 years old, length of time in UK five years, caring for husband aged 42 with diabetes and mental health problems)

**Discussion**

Although in recent times there has been greater awareness of the experiences and disadvantages faced by ethnic minority carers, there has been little in the way of practical change. Work by Mirza and Sheridan (2003) has highlighted how black and minority ethnic women draw on specific cultural knowledge and social resources when encountering health services. Our analysis suggests that levels of social capital may be inhibited by the exclusionary practices of welfare institutions and that in the lived space of these women’s lives the specific cultural and social resources available to them may further disadvantage them in their tactical struggles. As Bourdieu reminds us, well-intentioned interventions aimed at enhancing social capital may inadvertently replicate or reinforce divisions of class, race and gender. This generation of women were brought up in Bangladesh according to the customs of the time. Their children, however, have been socialized in the UK and have access to both Bangladeshi and British attitudes and values. Given the erosion of the extended family network, the trend towards smaller family size and the increasing numbers of females involved in the formal labour market, the space for caring may become more constrained. The demands of care provision affects the social, physical and emotional aspects of the lives of the carers. In this study, the majority of women were caring for a spouse while others were caring for a child with disabilities or elderly in-laws or parents. Caring duties were often extensive, including help with eating, dressing, bathing as well as assisting with mobility. Their roles as carers often went unrecognized or unsupported by service providers. They did not know about services available to them or about appropriate benefits they were entitled to receive.

Our study is limited in terms of the inferences and generalizations that can be made from qualitative research. Furthermore, the analysis presented here is a secondary analysis of data from a study whose original design did not focus on informal caring. However, the analysis is based on a large sub-sample of the original data comprising women who were engaged in informal care. By drawing on understandings of habitus and field, we have focused on the ways in which the dispositions and practices of the women influenced their routines of care and how expectations that accompanied these dispositions placed additional constraints on their lives. Furthermore, we have explored how conflicts in the fields of welfare revealed the women’s lack of knowledge and uptake of entitlements. These were mani-
fested in misunderstandings of both the tacit and formal rules of welfare. In particular, gaps in services and breakdown in relationships between carers and service providers may be related to misunderstandings over the rules of the game and imbalances in the resources available to these women when engaging in struggle in the field of welfare.

**Conclusion**

Bourdieu emphasizes the complexity of the interactions in the field of local powers and relates this to the extent to which certain groups in society are unable to grasp hidden bureaucratic rules. The gaps in access to formal support faced by the women in this study suggest that they experienced strong cultural and structural forces that determined their experience of informal care and the meanings they attached to their role as informal carers. 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. This study confirms these findings. However, by drawing on the work of Bourdieu and others, we suggest 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 to accommodate a more rounded understanding of relationship between habitus and conflicts over local fields of welfare.

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