‘Normal disruption’: South Asian and African/Caribbean relatives caring for an older family member in the UK

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Abstract

Little has been written on informal care of an older relative among minority ethnic groups in the UK. This paper examines the meanings of being an informal carer of an older family member for South Asian and African/Caribbean carers. The analysis presented here is based on qualitative interviews with 21 African/Caribbean and 15 South Asian carers. Drawing primarily on the notions of biographical continuity, biographical reinforcement and biographical disruption, the meanings of caring are examined. The findings indicate that the experience of informal care has many similarities to the experience of chronic illness. Carers generally described the experience of caring as an accepted part of their biography, talking about their caring relationship in terms of their pre-caring and a continuation of their previous relationship with the person being cared for and their roles within the family. However, the participants also described highly disruptive elements to this change in the relationships. The paper attempts to consider the relationship between individual experiences, cultural factors and macro-social structures.

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Introduction

Informal care is a difficult concept to define but any definition should ‘include reference to the unpaid care, ranging from round-the-clock tending to occasional acts of assistance’, provided by family members or friends to individuals who are disabled, chronically ill or need support because of old age (Offer, 1999, p. 469). Whilst this notion of ‘informal care’ is not uncontested, we are using the term as it is commonly understood to describe a group of people who share the experience of caring responsibilities outside of any paid employment. The issue of informal care has become an increasing concern since the 1970s—promoted in particular by feminist analysis and the shift away from idealist modes of thinking about welfare matters (Offer, 1999). The upturn of interest in this area has resulted in the introduction in the UK of policies aimed at this group of service users in particular, including the Carers’ Recognition (Support and Services Act) (Department of Health, 1995) and the Carers’ National Strategy (Department of Health, 1999). However, emphasis remains on co-operation between the state and the family for the provision of care. Informal care, particularly by the family, is still the most important source of care for the majority of older people (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). This is particularly so for carers of South Asian and African/Caribbean heritage because of the tendency to
Methods

The study reported here was an exploratory qualitative study examining the experience of caring for an older family member, focusing on ethnic minority carers of a person with dementia. The study used maximum variation sampling (Patton, 1990) to capture a range of caring relationships and individuals with diverse backgrounds. The sampling dimensions included gender, age, the carers position in family, degree of support required by the family member, ethnicity and socio-economic position. The sample was recruited through a range of public and voluntary services, including voluntary day centres for South Asian and African/Caribbean people (13); Alzheimer’s organisations (8); Community Psychiatric Nurses—from an Elderly Mental Health Team (4); generic carer support groups/carer support services (4); and General Practitioners (2). A further five participants were identified by snowball sampling or recruited opportunistically through attendance at carer’s meetings.

The data presented here are drawn from in-depth semi-structured interviews conducted with 36 carers who were from London, Bristol, Leicester, Bradford or Nottingham. Within the sample was a range of caring scenarios, although the majority were women caring for a family member with cognitive impairment, and most lived with the person being cared for. In 24 cases, respondents were the only person responsible for the care of their relative, however, 12 were in shared caring arrangements.

The interviews were guided by an interview schedule (or ‘topic guide’) and were open-ended to allow for the discussion of issues raised by the participants themselves. Information was collected on household composition, occupation and the carers’ social networks as well as eliciting the carers’ narratives regarding how they came to be carers, their motivations for doing so and views about their role and experiences.

Research participants were informed that the research concerned their experiences of caring for an older family member; they were assured of the confidentiality of the interviews. The interviews generally took place at the research participants’ own homes. On the four occasions where this was not possible, three participants were interviewed in a quiet room at their place of work, the other in a cafe. As the interviewer (JA) did not speak any of the South Asian languages the authors felt it more appropriate to offer an interview in the language of the respondent’s choice, facilitated by an interpreter, rather than exclude potential respondents on the basis of language. For three of the research participants an interpreter facilitated the interview. Two different interpreters were used, both were female, qualified in interpreting and were not related or known to the participant. The strategy was to attempt to keep the relationship with the interpreter as non-hierarchical as possible and the data was created within the three-way relationship between the interpreter, the respondent and the interviewer. At the end of each of these interviews there was a discussion with the interpreter about the interview, within which any areas of possible misunder-
standing were considered. Whilst these interviews were generally more stilted and perhaps produced less rich data, than those without an interpreter, they still provided valuable contributions to the study. Further issues relating to the use of interpreters have been discussed elsewhere (Adamson & Donovan, 2002), however, whilst the information gleaned from these interviews was generally presented less fluidly, the themes emerging were largely the same as for those without facilitation by an interpreter. The interviews lasted between 45 and 120 min, were tape recorded and fully transcribed. For two interviews, where tape recording was not possible (refused consent), notes were taken during the interview and written-up immediately afterwards.

The interview transcripts were systematically scrutinised and coded using constant comparative techniques to facilitate the exploration of themes and the identification of negative cases (Glaser & Strauss, 1967; Strauss & Corbin, 1994). The interview material was not considered as a description of an experience ‘external’ to the person giving the account, but rather, as described by Kelly and Dickinson (1997), the account is the experience, after the event and the meaning of that experience. Therefore, the analysis did not merely consider the descriptions provided only at face value, but were considered for what they could tell us about representation and social organisation (Bury, 2001; Silverman, 1997). Data collection and analysis were concurrent, interviews were carried out in groups of approximately five and then analysed. This analysis informed further sampling, any changes to the topic guide and subsequent themes of analysis. For example, although the research was focusing on carers of a person with dementia, for theoretical reasons it was felt respondents caring for an older person with other conditions should be purposefully sampled. Transcripts were coded according to analytical headings, informed by the topic guide, the literature and themes emerging from the data. All segments of text relating to each of these headings were then collated and used as the basis for developing detailed descriptive accounts of the findings. This enabled comparisons to be made of different caring experiences and how this related to the context in which caring took place. Both of the authors were familiar with the sociological literature on the experience of chronic illness and had noted many similarities between the analytical headings emerging from the process of data analysis leading to theoretical development along this route. All data have been anonymised and pseudonyms have been used for the presentation of findings.

During the process of analysis the transcripts of interviews with African/Caribbean and South Asian respondents were considered separately at first, then the findings from each were compared. Again it is important to stress that the terms African/Caribbean and South Asian are being used with the understanding of the diversity of the individuals falling within these broad and socially constructed groups. Within the African/Caribbean group the majority of respondents originated from Jamaica, however, some of the other Caribbean Islands were represented although not in large enough numbers to effectively compare between the different groups. The South Asian group were more diverse including reasonably equal representation of respondents originally from Pakistan, India and Indian communities from East Africa. Again these groups were small, making detailed examination of any difference between these groups difficult. However, when comparing accounts of the caring experience and the ways in which respondents transformed this role into their identity, the material showed little evidence of any major differences between these small groups in terms of the ways in which they thought about caring.

Findings

Caring as ‘normal’ aspect of biography: Biographical continuity

The concept of ‘biographical confirmation or reinforcement’ lends itself well in helping to understand the experience of caring. Originally proposed as a critique of Bury’s concept of biographical disruption, the work of Carricaburu and Pierret (1995) and Pound et al. (1998), focused on the normality felt by some individuals after the onset of a chronic illness, depending on the nature of their biography up until that time. For example, Pound et al. (1998) found many of her working class participants from London’s East End experienced stroke as a ‘normal crisis’, which made sense in the context of age, patterns of co-morbidity and the general adversity experienced throughout their lives (Pound et al., 1998).

Some of these participants indicated that they did not start ‘being a carer’ when their relative became ill in need of greater support but that caring was in some sense already integral to their, ‘biographically embodied sense of self’ (Williams, 2000). For spouse carers in particular, taking on the role of carer was often a continuation of their ongoing identity as partner and that this was an expected outcome of the bond and the commitment they made to each other when they were married. For example, during interviews with spouses it was never really discussed how they came to be the person responsible for care. These participants did not appear to regard themselves as ‘carers’, rather they suggested that they were doing what was natural. African/Caribbean spouses in particular referred directly to the marriage vows ‘in sickness and in health’, that whoever became ill first, they would be cared for, whereas South
Asian spouses were more likely to express this in terms of perceived cultural norms.

**Eddie:** If a man marry a woman, or woman marry a man, they are committed until death. I knew I was committed and I did not look after her because she had Alzheimer’s, no matter what caused it I would [African/Caribbean, husband].

**Shabana (via interpreter):** Being a Hindu lady, you know, we believe that we have to look after our husband, you know, and I think that is what we are brought up... I always believe if you are married that is your husband—you have one husband, look after him, that is our belief [South Asian, wife].

When a family member other than a spouse was the main carer they were more likely to have specific ‘reasons’ for taking on that role, particularly if they were the main carer over and above other family members. Within the caring narratives there were implicit ‘hierarchies’ which described who within the family was ‘expected’ to provide the mainstay of informal care, but also who was expected to support the main carer. This introduces another element of biographical continuity, whereby it was generally those individuals who historically had taken charge/responsibility:

**Paulette:** Well that decision was sort of made, you know, it just happened because I’m the eldest of four and my sister—we lost two sisters, two middle ones, so it’s just the first one and the last one who are alive. But, I’ve always been the one, you know, to see to mother’s affairs and so it’s been like that. I think as the eldest it was expected of me and because I have been willing [African/Caribbean, daughter].

Being the person within the family who was ‘known’ to have these types of responsibilities generally coincided with who was co-resident with the older family member before the need for care had arisen (and, therefore, perhaps for whom it would be seen to introduce the least disruption). This pattern was especially decisive where different siblings were potential sources of care. The South Asian participants were more likely to be in a joint household with a son and his family.

**Nasreen:** The eldest son is [responsible] and their daughter-in-law. It comes down to the daughter-in-law, not to the eldest son, it’s very rare you see an eldest son doing it, it’s always his partner who takes over the role... it’s the wife that does it [South Asian, grand-daughter (co-carer with her mother-in-law)].

Although this was not always the case, the notion that this pattern was more common was verified when those outside of this arrangement had to explain why they caring over and above the more obvious family member.

**Bobbi:** [my mother] used to live with my brother, but his wife was very ill with cancer. Then when my mum had the bowel problem, she came to stay with me just for a little while. She had no intention of staying for long, she came here just thinking that she would get better, then she would go back and stay with my brother. Then she became worse, she couldn’t do what she used to do before and then my sister-in-law, she was very ill and was in bed. So it wasn’t good for her to go back and [my sister-in-law] wouldn’t have been able to look after her anyway [South Asian, daughter].

For those being cared for by African/Caribbean participants, it was most often a daughter with whom they had shared a household before they needed care. For example, Winnie and Jim shared the care of their father, an arrangement that had happened gradually over time as they were living with him in the original family home. This could be described as continuity of roles within the family, as the need for care generally has an insidious onset (parallel to the insidious onset of the older person’s chronic illness).

**Jim:** I suppose we started looking after him just because we were still here living with him, no other reason. Up until [his father] was about 70, he was very able to look after himself anyway [African/Caribbean, son].

The need for continuity of shared living space in the same house as the relative in need of care was strong enough in some circumstances to over-ride the more ‘normal’ roles within the family. Whilst generally an older relative in the South Asian families lived in a joint household with a daughter or a son and his family who provided the care, this was not universal. Other relatives who already lived with the person in need of support carried out caring duties in precedence to other biologically ‘closer’ relatives who resided elsewhere. Mayuri, for example, a grand-daughter, explains her caring role, again emphasising that the disruption of caring would be less for her than it would for other family members:

**Mayuri:** When I was 11 I came to live with her. So, I’ve been living with her since I was 11 and I’m going to be 24 this year... me and my brothers are the main ones that look after her... I think it’s because we happen to live with her and all plus of them [cousins], they’ve sort of got their own lives. They work and go to the gym or the pictures or socialise with their friends and they don’t have time for their gran basically [South Asian, grand-daughter].

**Cultural connotations of informal care**

Carriacaburu and Pierret (1995) described the concept of biographical reinforcement, whereby the individual’s
life story could not be separated from the collective history from which they belong. The participants in their study dealt with their infection with HIV through the reinforcement of their pre-infection identities based on their sexuality or having haemophilia. In this way, the interviewees attempted to find continuity in their biographies. Evidence for this concept was found among these study participants, as many of the narratives included a reinforcement of their ideas of their own collective history and how this impacted on their interpretation of their role as carers. There was evidence that such norms were constructed in relation to, as Atkin, Ahmad, and Jones (2002) phrase it, ‘the perceived opposing values of out-groups’ (p. 22). For example, in some interviews this was expressed by participants reinforcing the concept of their ethnicity and, in particular, how this differed from the views, as they saw them, of the majority population. However, whilst these discussions may have been influenced by a white researcher, this is unlikely as Katbamna, Bhakta, and Parker (2000) also found their respondents (interviewed by South Asian respondents) to have the same misunderstanding that white women were not subject to similar normative expectations.

Selvi (interpreter): She said initially, that culturally and religiously she feels it is their duty to look after her and that they have no choice, that sons look after their mothers anyway—it’s not like English culture where people live on their own. The South Asian culture, she says that Indian or Pakistani, culturally they look after their relatives it comes down to the religious and cultural past [South Asian, daughter-in-law].

Millie: I wouldn’t like to be put in a home over here. We don’t put away our people in Jamaica, we look after them at home [African/Caribbean, wife].

Leila: but the way we were brought up is that you look after your own sort of thing. We’ve always done that, we never sort of think about it... ‘cause you think to yourself, “gosh what are people going to think, that I don’t care about her”... you just do it automatically cause it’s part of our culture, more or less you know, you don’t think of it any other way really [African/Caribbean, daughter].

Nasreen: I think my mother-in-law just did what was expected of her, she felt it was her role and she was fulfilling her role the duties within the role. They don’t see themselves as carers, they see it as part of their lives, part of their duty... It’s the way they’re brought up, they get married they take care of their husband, if they have children they take care of them, if their mother-in-law, father come into the picture they take care of the all the husbands side of the family. They take on that role... A South Asian person they wouldn’t see a carer whatsoever [South Asian, granddaughter (co-carer with mother-in-law)].

Interestingly as the quotes above demonstrate, these views were not limited to any one of the ethnic groups represented in the study. Selvi, an Indian Sikh, talked about her perception of the influence of her culture in her role of informal carer, as did Nasreen (Pakistani Muslim). Perhaps more strikingly the perceptions expressed by some of the African/Caribbean sample were also very similar, using their culture to explain why they were caring. This leads us to believe that these individuals are not caring because of their cultural heritage per se, but use their cultural heritage, drawing on biographical continuity and reinforcement, in the process of formulating their identities as carers. This is demonstrated further below.

For some the cultural explanation of care was expressed as a reinforcement of their role as a follower of a particular faith and this was common to all the religions represented in the sample. For example, Delores was a Christian and Jamshid was Muslim:

Delores: Well I think it’s a duty, because I think the lord have given me that problem, because he sends us here and we have to do a job [African/Caribbean, wife].

Jamshid (interpreter): he has no choice if he is a true Muslim... according to religious teaching, if he goes by that then he should look after his father [South Asian, son].

As stated above South Asian and African/Caribbean participants of all heritages and religions talked about the impact of culture, however, it was expected that those from minority groups would draw on their ethnicity, or more specifically their religion, in describing their identities (Modood, 1997). Respondents appeared to be talking about informal care through reinforcement of their existing biographies, which for some, confirmed to themselves that they were doing the right thing. This concept will be explored further below.

Moral narratives of caring obligations

The reasons individuals gave for taking on the caring role resonate with what Bury (2001) describes as part of the ‘moral narrative’. Bury (2001) describes moral narratives as those which introduce an ‘evaluative dimension into the links between the personal and the social’ (p. 274). By this he seems to be referring to moral considerations that connect family background and particular social context in which events occurred to the chronic illness (and in this case, caring) experience. Narratives of care can help to explore the nature of disrupted experience, its meanings and actions taken to
It would appear from the accounts of carers that caring for a family member at home is the ‘virtuous’ solution to the need for support—this was commonly expressed in terms of the undesirability of seeing their relative end-up in a nursing home, which seemed to be the only ultimate alternative. The reasons for this being the moral thing to do were plentiful. There was evidence of feelings of reciprocity for care received in the past and for the love that comes from a longstanding relationship with another person, which were often expressed as ‘duty’. In some accounts this was not a reluctant duty, but this depended on the relationship to the person ‘duty’. In some accounts this was not a reluctant duty, but this depended on the relationship to the person being cared for and the history of the relationship. For some, duty appeared simply to do with the position in the family.

The accounts were also peppered with the flavour that it was not only personal duty but also duty related to societal views regarding what was the culturally moral stance with regard to caring for family members. In part this may have been fuelled by social policy on informal care.

Nasreen: Somebody could be saying, ‘oh, they’re sending their mother-in-law to the day centre, it’s wrong, they shouldn’t be doing that, they should be taking care of her, so many people in the family’... But that’s how people think, it’s not only within the family they are pressured, it’s also others around them in the community [South Asian, grand-daughter (co-carer with mother-in-law)].

These forms of ‘duty’ were not mutually exclusive and a combination of several of these factors could be found in the same caring narrative.

Winnie: There’s no pressure, because I wouldn’t want to put [my father] into long term care. I wouldn’t feel—I mean it’s very strange for us, because my mum died when we were really young. I was 8 months old and Jim was 5 years and he’s brought us up and he’s worked very hard and it would seem like such a betrayal to think, right, we’ve got our lives now, you know, we’re going off to get on with it. So, it wouldn’t be right, he worked so hard, because there were 5 of us under 5 years and it was a hard job. I just think half of it was pay back, this is you know, I certainly wouldn’t be involved in that being an option [African/Caribbean, daughter].

Leila: You’ve got to remind yourself, well you know, it’s your mother, she gave up an awful lot for you, you know, it’s small enough to do for her... I don’t think you can ever repay your mother for what she’s done, I don’t think you can—but you can go some way towards showing her that you do care about her and you do appreciate her and all the things she has done... I do it for my mother, out of sheer, because I love her and care for, care about her, not because of totally what she did [African/Caribbean, daughter].

Although there were some exceptions, mostly spouse carers, the moral obligation to care was generally more strongly felt by women than men. The gendered nature of informal care is well documented in the literature, for example, Glendinning (1992), Lewis and Meredith (1988), and Opie (1994) and is reflected in the proportion of male to female carers, women were increasingly likely to look after parents and parents-in-law during the 1990s (Hirst, 2001).

Elaine: I mean, the relationship with my brother was quite strained for quite a while as you can imagine, because he didn’t actually sit down and talk about it with us. So, he like, he was having these feelings that he can’t cope or he feels it’s time that he lived his life. He just said one day, well I’m moving out and that was it, no discussion. So, we had a couple of arguments about that, he just said he’d come back and help us and he does. He does his little bit I suppose, but it’s never enough really. It’s not the same as being actually here because if I want to go out, I’ll have to like sort of leave her on her own or I have to sort of like say to me brother, “Are you around, can you come and visit your mum?” But he works shifts anyway because he’s a bus driver so it’s very difficult to co-ordinate that. I mean, he does comes up about three to four times a week to look after her which I take the time to go out. I mean physically go out, I go out the house [African/Caribbean, daughter].

Whatever the source of the feelings of duty and obligation to care, the fact that this was regarded as the right thing to do was communicated in several ways. For example, some carers wanted to maintain an image of keeping their moral integrity, in particular, this manifested on occasions when participants explained why they were not caring, which perhaps indicated that they felt other people thought they should be doing more and wished to present with a reason to legitimise this decision in the public domain.

Olivia: [Mother] could stay down here [at Olivia’s house] with me but it’s not appropriate, again the bathroom is down here the bedroom is [upstairs] so she couldn’t… if it wasn’t like this I might think maybe she could have one of these rooms down here but she can’t…

Int: I mean if the house was set up differently do you think she would have been here by now?
Olivia: Yes, because it would be much easier for me and more peace of mind because I would know that she's upstairs and I could run up stairs and give her and come down and know she's alright but then it takes me a few minutes to walk over her flat to see if she's alright [African/Caribbean, daughter].

Reasons included other pressing commitments that made living with the person needing care impossible. These were always factors that were required for alternative aspects of moral integrity such as keeping employment to maintain a standard of living and were used as justification for who should care:

Cheryl: So, what happens is, the home help comes in the morning and gets her ready, the van picks her up and she comes back here at 4.30 and my brother comes to meet her... Because my brother, he's the one that comes here... he's redundant and he's been out of work, he has the odd job but he's the one that comes here every single afternoon and sits and waits. He's the one who has to wait here 'till someone comes and he's here until 8 at night [African/Caribbean, daughter].

This aspect was particularly strong in the accounts of family members who had needed to put their relative into full-time care accommodation. For example, Jean could no longer continue with employment (as a nurse working shifts) and caring for her husband at home, as she could not afford to do so:

Jean: At weekends I get sleepers in, but I can't afford to keep getting the sleepers in and get somebody to stay with him during the daytime while I get some sleep. So what I do, I get him up when I come home—when I come home from work get him his breakfast and then I'll go off to sleep for an hour or two and listen for him and come and give him his lunch... if they were going to pay my bills, all the bills, so got to go to work... like if someone else said 'oh we'll pay a certain amount and I can work one night to get away that would be fine, but they're not paying me nothing you know [African/Caribbean, wife].

The moral role of caring was reinforced through the ways in which some of the participants indicated that they had been afraid to talk about caring in a negative way. In many accounts it was as though the participants needed 'permission' from others complain about their situation.

Leila: [the catholic church] have helped me tremendously... one time when I was really bitter I went down and the nuns were marvellous. Sister Mary was great, she said, 'you're allowed to feel that way', you know, and that really helped me—we had lots of little sessions just her and me and she's a great women and has helped tremendously [African/Caribbean, daughter].

This notion of needing permission to have negative feelings about caring has many parallels with Bury's (1991) concept of legitimisation, referring to attempts to maintain a sense of personal integrity in the face of a disruptive experience.

The ability to ‘complain’ or at least express that there were difficult aspects to caring for a relative appeared to have been helped by the raised profile of informal carers over the last two decades and the consequent ‘official validation’ of the role of carers and the disruption this can cause to the individuals involved. At the same time, much of the legislation which has surrounded informal care has also reinforced the notion that caring is the moral thing to do. For example, the 1989 White Paper Caring for People (Department of Health, 1989), legitimised the view that informal carers were the main orchestrators in care provision, to be supported by statutory services. This is further reinforced by the use of emotive language, for example, Tony Blair describing informal carers as the ‘unsung heroes of British life’ (Department of Health, 1999). Therefore, a moral imperative has firmly been placed on families to function as carers of the sick, disabled or elderly (Heaton, 1999).

This was expressed by the participants as performing a legitimate and worthwhile role from which they derived much self-esteem, in particular, because it was something they were good at.

Bobbi: I think I feel... I feel as if I’m doing something good, you know. And it’s actually good for my children as well, because they learn, you know, how to look after an elderly—like when we grow old and are older you know. They know what it is to be, what it is like to be like an old person [South Asian, daughter].

Ron: Nobody can cope with her like me, nobody would have the patience you understand... I have the patience to feed her and to cope with her [African/Caribbean, husband].

Carriacaburu and Pierret (1995) indicated that whilst their respondents’ HIV status reinforced components of their identity that were built around haemophilia or homosexuality, they were also keen to emphasise that whilst these individuals may not have experienced biographical disruption in the previously defined sense, they were still ‘menaced’ by their HIV status. As the above demonstrate, informal care was in some senses a continuation of previous roles within the family and through the reinforcement of certain aspects of their biography, carers were able to better understand their caring role as an accepted part of their lives. This is not to say that the experience of caring was not a highly
disruptive one—the disruptive nature of caring will now be discussed.

Caring as biographical disruption

Sanders, Donovan, and Dieppe (2002), found that when their participants talked about their experience of osteoarthritis, whilst they portrayed their symptoms as a normal and integral part of their biography, they also discussed the highly disruptive impact of symptoms on their daily lives; the experience of caring can been understood in a similar way.

Meaning as consequence

Bury (1988) outlined that one of types of meaning that could be ascribed to the experience of chronic illness was surrounding its practical consequences for individuals and their families. Here he was referring to the effects of chronic illness on everyday life, including the implications for finances, employment, personal care and practical daily living. The notion of ‘meaning as consequence’ was also reflected in the carers’ accounts of the impact of caring on their everyday lives. The carers described several of the practical consequences of becoming a carer and those were very similar to those relating to chronic illness.

Mayuri: It’s a bit hard because I can’t exactly change jobs now. I mean I’ve tried but I think it would be really difficult... where I’m working here I’ve been here for four years and they know everything about me and my gran, so they are really lenient as well. Like the Wednesdays off situation, they said we’ll sort something out, and they will give me Wednesday off. The money’s not that good, I was hoping to get another job, but with my grandmother, I don’t think I could, because the next company might not be as lenient [South Asian, grand-daughter].

Nish: Before we used invite people for dinner and I had to do a lot of cooking. We were going to other people’s houses for parties and dinner before. But now we have to stop that and I can’t go in the evening because I can’t leave my husband home and I can’t take him—nobody invites us any more. Two years back, some people were inviting us even still but now everybody has stopped inviting us because he can’t... So they don’t invite us anymore [South Asian, wife].

Caring for a relative had consequences for all of the participants in some form, whether concerns with employment or social life as described above or physical and emotional consequences.

Taz: Suddenly, I had a pain in my chest—I mean the pain came to me, but I was fully aware that one day I might fall ill like this. The doctors told me to be safe and consider it and take it easy and all this, but I can’t find—you cannot take it easy, you are neglecting because there is no one to help you. I think it is a result of my strain, there is no doubt about that [South Asian, husband].

Ellena: If you are just sitting here, you can’t speak in the morning, with all your brain going as well—you feel more depressed I think. Just thinking the same thing all over... I am very emotional sometimes, so I just go to my bed and cry—that’s all I do [African/Caribbean, wife].

Commitment to anticipated future

As is the situation with chronic illness, some individuals conferred a ‘less than disruptive gloss’ on what for others may appear to be a fairly miserable existence—it appears that time and context, norms and expectations, alongside commitment to events themselves, anticipated or otherwise are crucial to the experience of caring (Williams, 2000).

Some participants were finding caring profoundly disruptive and this was particularly the case for those individuals who wanted a future which included features which were no longer possible, in the short term at least, due to caring for their relative. As Bury (1991) described, referring to chronic illness, meanings surrounding illness often change as they interact with different stages of the life course. This was evident in the different reactions to caring given by the participants.

Paulette: You know because retirement was going to be the time when I was going to be able to do all the things that I wanted to do when I was working. You know, get my house up together, get my garden up together, maybe not tour the world but, you know, you could get up and go when you feel like it. Or if somebody invites you out at the spur of the moment you could just go. But now I can’t do that and people say to me ‘how are you enjoying retirement?’ and I say ‘what retirement?’ You know I’ve only retired from paid employment and that is a fact [African/Caribbean, daughter].

Such disruption was more commonly felt by the younger carers in the study, expressing conflicts between their present circumstances and the ideas they had held about this time in their lives.

Elaine: I think maybe if I’d been in my late thirties or early forties I wouldn’t feel these feelings that I’m having now because I’d think, well, I’ve had my family, I’ve lived my life. I’ll just have a caring role and that’s it, but because I’m still young, I was what only about 20, 21 when it happened. So, I was still quite young as well [African/Caribbean, daughter].
The effect of age on the disruption felt following the onset of a chronic illness was highlighted by Pound et al. (1998). The authors described that, despite the considerable impact of stroke, the idea of a ‘happy before and a tragic after’ was only reported by two respondents who were at a relatively young age at the time of the stroke. In this study, this was also evident, for example, one of the older carers was not finding caring particularly disruptive as she felt she could fit her caring role within her other commitments:

Selvi (via interpreter): She doesn’t feel that her mother-in-law stops her from anything because she has got plenty of time on her, because she has not got little children like with the family who has got small children it is really difficult for them to get the children ready to get them to school and all that [South Asian, daughter-in-law].

Caring appeared to be the most disruptive for those with the greatest number of competing interests, whether that be employment, children or the pursuit of pastimes.

Anticipated support from other family members

Another strong source of disruption (and dissatisfaction) came from the support with caring, or rather lack of it, from other family members. This is linked to the implicit ‘hierarchy’ of caring responsibilities within families, where it was generally prescribed who would provide the main caring relationship, but also who was expected to support them in this role. When these expectations were not satisfied, considerable disruption, particularly to family relationships, was the result. For example, as the quote from Elaine above described, her brother had been living in the family home but had left when their mother became in need of support, leaving a strain on their relationship. Likewise, Mayuri was not receiving the support she expected from her aunt and this was causing her much angst.

Mayuri: I wish my dad’s sister would [help out more]. My gran’s daughter, because she only comes once a month, plus my gran gets on with her as well. She’s the one person my gran doesn’t scream at…. They’ll all sort of comment on ‘oh you should do this and you should do that’ to me—everybody says that, and it’s really frustrating. I’d like to say to them, ‘why don’t you come in and do your piece and do it yourself?’ Like my dad’s sister, she comes and she says, you know, ‘you should cut her nails and you should do this and you should do that’ and it really frustrates me because of the fact that she only comes once a week. She’ll come at four and say, “I’ve got to leave really early”, ‘cause her husband gets frustrated while she’s not there [South Asian, grand-daughter].

As Brown comments (see Williams, 2000), social support may have a moderating effect in the disruption caused by caring. Winnie, who was sharing the care of her father with her brother, experienced caring as disruptive, but she was able to manage well with the support of other family members.

Winnie: Everybody’s reasonably local, everybody just does a bit… Jim and I do the main bits because we’re here, but the other day I was going off somewhere and Jim was going off to cricket and Saturday’s not a day I want to leave him here on his own as I think it’s a bit of a long day. So we tend to, I rang my brother and my brother had him up at his house for the day so we can usually… the only lucky thing is I share it with Jim, so if I can’t do something then he can—we can always work something out, and if we get really stuck then one of the others will help, but we can always work something out [African/Caribbean, daughter].

Hatty: I was looking after him when we had an agreement that all three of us should be taking responsibility to look after him, you understand? My brother have him two days of the week and the other one have him two days and I have him two days, you know. I was prepared to have him more days than them, “oh you have him for a week”, you know. Then when they take him back they say that it’s making him confused. He’s already confused, you know, so what difference would it make? At least it would be giving each one of us and be giving the other one a break, but, they thought, I’ve retired and I have a home, I don’t have anybody so it is easier for me to have him. But I felt they should have him because they were brought up inside his house you know, he looked and cared for them, he didn’t for me [African/Caribbean, daughter].

It was demonstrated above that caring was seen as the most moral action, apart from when other aspects of moral life were in jeopardy because of the caring relationship. This also impinged upon how disruptive the experience of caring was. When other factors held as a moral duty, such as child care were being threatened, carers found this very disruptive. For example, Jamshid was worried about the impact caring for his father was having on his children.

Jamshid (via interpreter): his wife is mentally feeling ill, that the children are upset because they can’t sleep at night and they can’t get up in time for school. His father forgets and sometimes, late at night, he goes into where his wife and the daughter are sleeping and he literally laid down, you know, on the daughter and she started to scream in the night [South Asian, son].
Likewise, Nish was worried that keeping her husband at home was having a negative effect on her son.

**Nish:** He didn’t understand, my son, what was happening to [his father] and why he’s doing things and why he is behaving like that. He was too young to understand and he became very aggressive and he was behaving very—I would say, not properly, so I started getting worried about this. I was worrying about him mainly because he was not doing any study, he was not doing anything, no helping anything. He was becoming very violent at sometimes, shouting and things. I started getting worried that this illness is putting a bad effect on him and he might grow up in anger and so I am ruining his life [South Asian, spouse].

**Discussion**

This research has shown that the experience of informal care has many parallels with the experience of chronic illness. Carers could be said to ‘share the moral world of the chronically ill’ (Chamberlayne & King, 1997, pp. 602). The carers’ accounts located caring within a cultural framework that portrayed caring as a virtuous state and, therefore, in many respects the ‘normal’ and expected thing to do. For many carers this was a continuation of their previous role, for example, as a spouse, a daughter, a son, a daughter-in-law, etc., and a duty related to love, reciprocity, position in the family or a combination of these factors. Whilst these carers tended to interpret their caring experiences as part of their cultural heritage as individuals from minority groups in the UK, this is not to say that such notions of caring as ‘the norm’ are either unique to South Asian and African/Caribbean carers, nor by any means universal. More, this seemed to be reflecting the way in which the carers drew on their pre-caring life to adapt to and understand the new situation. But this was not because they were South Asian or African/Caribbean per se, rather this reflected their previous biography and self-identity. It would not be unexpected that those from minority groups would draw on their ethnicity, or more specifically their religion, in describing their experiences (Modood, 1997). However, it was clear that ethnicity was not the only aspect mediating the experience of caring.

At the same time, although for many carers caring was understood as an almost normal consequence of the ageing of family members, it was also a highly disruptive experience. This was particularly felt when the caring duties disrupted a commitment to a particular desired future. This depended on the life-stage of the individual carers, but was generally more acutely felt by the younger carers. This is likely to reflect the changing role of women, in particular, in modern society that incorporates an advanced sense of choice and reflexivity regarding how time can be spent on both career and leisure time. Other factors associated with a greater disruption were a lack of support from other family members and the inability to continue to fulfill other equally moral obligations, in particular, child care or meeting financial responsibilities.

There is a substantial qualitative literature focusing on informal care and in particular, examining the reasons for being a carer and the consequences of acknowledging that role. This work however, has mainly included white British participants, who were caring for people for a wide range of reasons. Yet the over-riding feature of comparisons with the findings from this body of work and that presented above are the stark similarities. For example, the carers narratives relating to how caring started were very similar to those observed in the previous literature and could also be thought of in terms of the chronic illness notion of ‘biographical continuity’. These include the way that some carers ‘drift’ into caring (Lewis & Meredith, 1988) especially those who are already co-resident with the older person (Glendinning, 1992) and for some a continuation of their roles within the family (Lewis & Meredith, 1988). The literature suggests a very similar caring hierarchy to that observed in this study, in which in the absence of an available spouse, the daughter is the first choice, single daughters being preferred to married (Lewis & Meredith, 1988). For spouses, caring may be part of their commitment to the relationship through keeping to their marriage vows (Opie, 1994; Wuest, Ericson, & Stern, 1994) and, hence a continuation of the ongoing relationship.

The social, moral and gender-based duty associated with informal care are a strong themes in the existing literature (Harris, 1993; Lewis & Meredith, 1988; Opie, 1994; Wuest et al., 1994). Ideas of duty being related to a combination of love, devotion and reciprocity (Duijnstee, 1994; Harris, 1993; Lewis & Meredith, 1988; Parsons, 1997). Again, these themes were evident in the participants in this study and are similar to the moral narratives that are produced around the experience of chronic illness. Such notions are reinforced by carers feeling that no-one else can care for their relatives’ as well as them (Harris, 1993; Lewis & Meredith, 1988), often leaving carers with positive feelings from fulfilling this role (Duijnstee, 1994; Parsons, 1997) and the experience of care a reinforcement of existing biographies.

In their study of family obligations Finch and Mason (1991) draw the useful conclusion that people do not carry around with them stable sets of values and meanings about obligations to kin, rather, they construct them when they have to out of various materials available. This conclusion, not only resonates with the
findings from this study, but helps us to understand the respondents constructions of their caring experiences and how this interlinks with their ethnicity and identities in general. It is the case that many of the carers in this study drew on their culture and ethnicity to help them to account for their role as carers. However, it appears that this group of carers, like most others, use biographical narratives to make sense of their situation, the only difference being the nature of these biographical identities as individuals in minority groups in the UK. Therefore, the processes individuals are using to make sense of their experiences of carers appear to be the same, from the evidence based on the majority population as well as the respondents in this study, yet those in this sample are using notions of identity and biography, which often incorporated issues of culture and ethnicity.

It is likely that carers expressing their caring role in terms of their ethnicity has been misinterpreted as ‘looking after their own’ and goes some way in explaining the perpetuation of this stereotype as caring being culturally specific. This should not, therefore, deter appropriate service provision to support carers from minority groups. This is reinforced by the simultaneous disruption expressed by the participants caused by the informal care, indicating similar problems to those that have been recognised through the caring literature for almost two decades. Like this study the previous qualitative literature based on largely white British samples have highlighted that carers do find caring to be a particularly disruptive experience, for example, finding the role hard work, difficult to endure, eliciting feelings of gloom and despair (Parsons, 1997). The literature has observed that caring has many consequences including jeopardising social relationships (Harris, 1993; Lewis & Meredith, 1988; Parsons, 1997) including with children (Wuest et al., 1994), employment, health, activities and interests (Harris, 1993; Opie, 1994; Parsons, 1997; Wuest et al., 1994). These themes were echoed in the South Asian and African/Caribbean family members appear to experience caring in largely the same way as that which has been described in the large literature on informal care based on the majority population. The processes these individuals use to understand the experience are similar, whilst the identities and biographies are of course grounded in the individuals. As Atkin et al. (2002) observed in their study of young South Asian deaf people, exploring identities is a complex undertaking and these were not based on notions of singular identities or a hierarchy of identifications—in this study individuals identified themselves across many axes, of which their ethnicity was only one vital component. Essentialised notions of ethnicity do not appear helpful in attempting to understand the experiences of carers from minority ethnic groups as the role of carer is not always mediated in these terms. The findings from this study should help to focus attention on encouraging the development of more sensitive service provision.

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