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Health & Social Care in The Community

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Do they look after their own? Informal support for South Asian carers

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Abstract

Policy on care in the community was founded on the premise that the care of frail elderly people with disabilities would be a joint responsibility for health and social care professionals, and family carers, supported by people within their social networks. The policy assumes that such social networks are common features of all communities in contemporary Britain, containing a reserve of people who can be called upon to provide support to carers. The present paper draws on material gathered for a qualitative study of the experiences carers in South Asian communities to examine the quality and quantity of informal support that was available in different types of households. Male and female carers were selected from the Punjabi Sikh, Gujarati Hindu, and Bangladeshi and Pakistani communities. A total of 105 carers participated in the project. Participants were caring for people in all age groups with physical and/or mental distress, and in some cases, with multiple and complex impairments. The analysis of carers' accounts suggested that, for a variety of reasons, the main carer, irrespective of gender, had limited support both in nuclear and extended households. In addition, societal attitudes towards disability and the fear of obligation prevented the seeking and accepting of help from wider social networks. The paper concludes that the evidence does not support the assumption about extended families, and their willingness and ability to support carers. Many issues highlighted in this paper have far-reaching implications for policy makers in many countries in the West where South Asian people have made their homes.

Keywords: nuclear and extended households, social support networks, South Asian carers

Introduction

The policy on care in the community was rooted in the idea that self-supporting social networks of families, friends and neighbours would form one of its central planks (Griffiths 1988, Parker 1991). However, there is a lack of understanding about the possible impact of the reform of community care policy on minority ethnic communities (Patel 1990, Ahmad & Atkin 1996).

The present paper explores South Asian carers' experiences of informal support. After a brief review of

relevant research and policy literature, the authors outline the study methods, sample characteristics and their mode of analysis. They then present the empirical accounts of the carers' experiences of informal support in nuclear households, extended households and in female-headed households.

The dynamic of social support networks

It was generally assumed that the implementation of policy on community care in the South Asian community,

where social or kinship networks are thought to be strongly rooted, would pose few problems. However, even if the will to provide informal care was there, strict immigration laws, a growing preference for nuclear households, occupational mobility, housing problems, and for many, the fragmentation of family networks made this a questionable assumption (Stopes-Roe & Cochrane 1990, Blakemore & Boneham 1994, Elliot 1996, Modood *et al.* 1997). Social and economic pressures, changes in marriage and divorce practices, and the increase in the participation of women in the labour market have placed additional strains on support systems and family ties (Westwood & Bhachu 1988, Drury 1991, Phillipson *et al.* 1998).

The existing literature on social support networks in minority ethnic communities is based largely on the nature of kinship ties between and within generations, and focuses on issues such as who in the kinship network is most likely to be approached for help, and levels of satisfaction with the support that is available and provided. For instance, the findings of Phillipson *et al.* (1998) revealed that the social support networks of elderly Indian and Bangladeshi people were mainly located within multigenerational households, and children and spouses were the primary source of support for elderly people. Stopes-Roe & Cochrane (1990) also reported that the presence of an extended kinship network did not necessarily signify a larger pool of potential support for members of the household. However, there is a dearth of evidence about the nature of support and about how members of the household, particularly those who care for a relative with disabilities, negotiate support from social networks.

Informal support for carers

The quality of informal caregiving is affected by the availability, ability and willingness of carers to provide care, as well as factors such as employment, housing, car ownership, the strength of social networks, the number of people needing care and the nature of the care needed (Finch 1989, Heath & Dale 1994, Ahmad 1996). Differences in family structure, migration and settlement patterns, and socio-economic circumstances have a particularly detrimental effect on the ability of South Asian families to cope with the demand of caregiving in an alien environment (Phillipson *et al.* 1998, Blakemore 2000). However, such realities are rarely reflected in the formulation of policy for minority ethnic carers and their dependants.

Moreover, the existence of a social support network is no guarantee that help will be freely offered or acceptable to carers and those they care for. For example, Turner *et al.* (1998) suggested that the gender, class and

employment status of carers, and their degree of attachment and integration into social networks, can have a major impact on the level of potential support. Support may also vary according to the type of carers and the nature of their relationship with those they care for. Negative attitudes towards physical or mental impairments (e.g. the stigma attached to mental illness or HIV/AIDS) may influence help-seeking behaviour. It has also been suggested that the attitude of the person with disabilities towards accepting help may determine the level of support that carers can expect. Conflicts with family or friends can have an adverse effect on caregivers' perception of the support provided, and in some cases, increase reluctance to seek support (Hussain 1997).

Contact with family and friends, or membership of organizations does not mean that support is readily available. For instance, Atkin & Ahmad's (2000) and Chamba *et al.*'s (1998) studies of parental carers suggested that practical or emotional support from the extended family was often negligible. In many cases, carers claimed that their ability to cope was actually compromised by unhelpful interference from relatives, including the 'moral policing' of the carers' performance. Hussain (1997) reported that carers of relatives with mental health problems were particularly isolated because of the stigma of mental illness. The need to maintain secrecy to preserve the family's reputation, or *izzat*, often took precedence over a carer's need for support.

Subjects and methods

The present study is based on the four main British South Asian communities: Punjabi Sikh, Pakistani, Bangladeshi and Gujarati Hindu (Katbamna *et al.* 1998). The aim was to explore the experiences and needs of carers, and to develop guidelines for primary healthcare teams to help them provide improved support to carers.

The limited knowledge about ethnic minority carers, the sensitivity and complexity of the range of issues to be addressed, and the diversity of issues and views which needed to be analysed and synthesised (Bryman & Burgess 1994, Silverman 2000), all indicated that a qualitative approach was required. Focus groups and in-depth interviews (IDIs) are highly appropriate methods where the research topic is complex, and where the objectives are explanatory and about generating as well as testing hypotheses. These methods offer several advantages for exploring complex and sensitive issues, allowing participants to engage in a dialogue in their own language and drawing on their life experiences to explore the issues which are important to them (Kitzinger 1995, Clarke *et al.* 1996).

Ethical approval was obtained for the present study. A series of three single-sex focus groups (FGs) was

organised to provide an opportunity for the participants to get to know each other, engender trust, and reduce their inhibitions about talking about difficult and sensitive issues. Discussion groups were followed by individual interviews to provide participants with a further opportunity to explore complex and sensitive issues more fully and in private. Most carers attended all three sessions. The groups were organised and facilitated by trained bilingual facilitators matched for the gender and language of the group concerned. The discussions and IDIs were tape-recorded and translated into English by the facilitators, and then transcribed (for a detailed account of the methods, see Katbamna *et al.* 1998).

Topic guides for the FGs were based on issues which arose during community consultation and a review of the relevant literature (Katbamna *et al.* 1997). These guides were flexible, covering broad issues, but also allowing emergent themes to be accommodated. The guide for the first focus group covered attitudes towards disability, personal experiences of caring and its impact. The second dealt with carers' experiences of accessing and using primary healthcare services, and the third looked closely at how services might be improved to meet carers' needs. The third focus group was also used to check the emergent findings from the first and second groups with carers. Information from the group discussions was then used to develop a guide for the in-depth interview. This looked in more depth at the experience of caring, its associated costs and benefits, sources of support from within the family and community, and access to and use of services, but again, were flexible enough to accommodate emergent themes.

Community and primary healthcare team liaison, word of mouth and 'snowballing' were used to encourage participation. Information about the project was translated into relevant languages and radio interviews were used in an attempt to reach those who might not be literate in their mother tongue. Purposive sampling was used to select a range of caring relationships and caregiving situations. The sample included carers who were caring for young and adult offspring, as well as parents, spouses, siblings and grandparents with physical and/or mental conditions, and in some cases, with multiple and complex impairments. The participants for IDIs were purposely selected from those who had taken part in FGs and others newly recruited to ensure that the range and mix of carers providing care in nuclear, extended and single-parent households. The age of the person being helped ranged from a 2-year-old child to several people in their mid-80s. A total of 105 male and female carers aged between 20 and 72 years participated in the project. Fifty-nine female and 27 male carers participated in the FGs, and 22 female and 12 male carers took part in IDIs (Table 1).

Table 1 Focus group and in-depth interview sample

Variable	Male	Female	Total
Focus groups	27	59	86
In-depth interviews	12	22	34
Carers participating in focus groups and in-depth interviews	6	9	15
New carers interviewed in depth	6	13	19
Total number of carers involved	33	72	105

Data analysis

The data from FGs and IDIs were analysed to identify and generate broad themes, categories and concepts from the transcripts of these sessions (Bryman & Burgess 1994). Each transcript was read through carefully to identify broad analytical categories and sub-categories suggested by the original topic guides, and new categories which emerged directly from the carers' accounts. Transcripts were coded according to key themes and sub-themes. A summary of key points was transferred onto charts. The key points, which reflected the range and the frequency of carers' views, formed the basis for generalising and comparing their experiences. The comparative analysis provided a basis for interpreting and explaining differences between and within groups, and between sexes. Further analysis and interpretations allowed patterns, associations and concepts to be identified.

The family structure and composition of British South Asian households are varied and complex (Ballard 1990, Ahmad 1996). The carers' experience of informal support is presented under four headings: (1) support within nuclear families; (2) support in extended households; (3) support in female-headed households; and (4) support from wider kinship networks.

Results

Support for carers within nuclear families

The majority of male and female carers in nuclear families cared for elderly spouses, or spouses, children, parents or siblings with disabilities. Evidence from the present study suggests that the main source of support for carers in nuclear families was other non-disabled members of their immediate family. For example, in the case of female parental carers, the commonest types of help provided by husbands included watching over disabled and other children in the family, taking children to school, and accompanying the child with disabilities to clinics and hospitals; husbands were rarely responsible for more intimate forms of care. Mothers of

children with disabilities reported that their husbands were the only source of the emotional support that enabled them to continue caring (Mir & Tovey 2003). The literature on carers suggests that, in most households, care of an elderly person or someone with disabilities usually falls on one person. The level and type of support available to the main carer depends on who else is living in the household and their willingness to assist the carer (Glendinning 1988, Qureshi & Walker 1989, Parker 1993). The presence of other family members in the household is not a guarantee of support for carers (Cameron *et al.* 1989, Cocking & Athwal 1990, McCalman 1990).

The level of satisfaction with the quality and quantity of support that mothers of children with disabilities received from their husbands varied enormously. Almost all mothers of children with disabilities in the four communities who complained about the lack of support from their husbands believed that the fault lay in the way men were socialised into thinking that child care was the sole responsibility of mothers. Consequently, they could not rely on their husbands for practical support, and even with a simple task, such as taking their disabled child to the clinic, was resisted and undertaken under duress:

I mean he [the husband] will come home and then slobber [sit around?], you know, and I keep thinking, 'Come on, you know, help me with these, giving the children their drinks so they can go to bed,' it's sort of like having to push him to do all the time. (Pakistani Muslim female caring for children aged 9 and 12 years with severe physical and mental impairments – IDI)

However, it was also interesting to note the impact of a gender-based division of labour on patterns of caregiving behaviour in a family. For instance, mothers made frequent reference to the fact that their husbands provided little support with many of the physical aspects of caring, but rarely mentioned that their husbands negotiated with officials, and organised help with housing adaptations or welfare benefits. A possible explanation for the perceived lack of support may be that these so called 'compensatory' tasks are seen as distinct from hands-on caregiving, and therefore, are taken for granted. The compensatory tasks undertaken by husbands are clearly necessary since they enable hands-on caring to be performed. It is only in the absence of a person to undertake such tasks, as we shall see later, that its significance is realised. Gender, children entering puberty, the nature of care and skills such as the ability to communicate with officials also impacted on caring divisions of labour.

Whilst mothers struggled on their own in some nuclear families, changes in caregiving circumstances forced parents in others to reassess their caring role. The need for support for mothers reached a critical stage when their sons with disabilities approached adolescence and

became too heavy to lift and carry. In such families, fathers assumed the responsibility of providing hands-on care with the help of their wives:

In the beginning, my wife used to look after him mostly, but now he is a grown man, the pressure is a lot more different ... Now it takes both of us to look after him. (Pakistani Muslim male caring for a son with physical and mental impairments – FG)

The sensitivity surrounding cross-gender caring is problematic for both carers and those being cared for. However, in nuclear families, the lack of a suitable person to help with intimate tasks can cause serious difficulties for both carers and their relatives with disabilities. Most spouse carers felt that neither their relatives nor the service providers appreciated their difficulties. A Gujarati male spouse carer reported that the disparaging remarks of his friends and relatives increased their isolation and undermined their ability to cope:

They [relatives] feel that I have changed. They say, 'Now that you look after your wife, you have become a women's man ...' What more can I say about this, it's very difficult to explain to others how you feel. (Gujarati Hindu male caring for a wife paralysed after a stroke – FG)

Evidence suggests that health and social care staff are generally more sympathetic towards male carers in the white community, and consequently, their needs are addressed more promptly (Arber *et al.* 1988). However, the present authors found that the same level of understanding was not extended to male carers in nuclear households. For instance, a Gujarati male caring for his widowed mother with severe arthritis and depression reported that he did not have any female relatives who could help him to provide personal care for his mother. After struggling alone for a few months, he felt that the only course of action open to him was to get married:

My mother could not do anything herself. I had to do everything ... clothe her, bathe her and feed her. I was not married at the time ... it was getting very embarrassing. I had to get married in the end. (Gujarati Hindu male caring for mother with severe arthritis – FG)

The literature shows that children are also an important source of support for carers (McCalman 1990, Beresford 1994, Shah & Hutton 1999). The present findings also suggest that carers in nuclear families received varying amounts of help from their children. In some families, they assisted the main carer with personal and practical tasks, including keeping a watch over their relative with disabilities and younger siblings, and in some cases, they acted as a negotiator or interpreter for the carer.

Carers' personal circumstances often determined the level of support that they required from their children: for example, additional responsibilities for caring for other dependent children in the family, the absence of

another available adult to share some of the responsibility, and difficulties with cross-gender caring and in negotiating with professionals. In the case of Bangladeshi families, some female spouse carers were entirely dependent on their non-disabled children since they had no other informal or formal support (Katbamna *et al.* 2002).

Accessing help from informal sources is problematic at the best of times for most carers. The difficulties for Bangladeshi female carers were compounded by the fact that their relatively recent migration to the UK had resulted in the fragmentation of kinship networks, and few opportunities to establish new contacts meant that they were forced to rely heavily on their children:

... [M]y daughter is the other [carer] ... She looks after my two sons who are sick and my 7-month-old baby. My 12-year-old son ... he does all the shopping and helps me bathe my husband. I don't know what I would do without their help. (Bangladeshi Muslim female caring for a husband with Menière's disease, a 14-year-old son with diabetes and another 11-year-old son with asthma – IDI)

Besides help with personal and practical tasks, children were often required to act as interpreters for their parents and also assumed responsibility for liaising with service providers. Although carers in the Bangladeshi and Pakistani communities were more likely to rely on children to act as interpreters, elderly female carers in the Gujarati and Punjabi communities also relied on children for interpretation:

The problem is, because I cannot speak English, I can't ask the questions that I want to ask. If I take my daughter ... she feels embarrassed and she doesn't ask everything that I want her to ask. (Bangladeshi Muslim female caring for an adult son with mental and physical impairments – FG)

However, the presence of children in the family was no guarantee of support. Several female carers reported that their adult sons did not accept any responsibility for the care of their relative with disabilities. A number of elderly female spouse and parental carers, who were finding it increasingly difficult to provide personal care unaided, were aggrieved that their sons were unwilling to help with intimate care:

Really, it's my son's responsibility that he should take care [of his father], but he doesn't want to take the responsibility. (Punjabi Sikh female caring for a husband paralysed after a stroke – FG/IDI)

In contrast, carers reported that their daughters were only too ready to help them. In some households, daughters often took over the whole responsibility when the main carer was ill or away from home:

I need a person with me all the time. My daughter stays with me when I feed her [a daughter with disabilities], we have to straighten her, re-warm her food. I was in hospital recently,

and she took over. But she's still young, she's still a child herself, and I don't like her to do more than she has to do. (Pakistani Muslim female caring for adult daughter with severe physical disabilities – IDI)

Male spouse carers also reported that their daughters helped them with household tasks such as cooking and cleaning, and with the personal care of their wives:

Normally, when my daughters come home from school, they do help me out, like making food in the kitchen, cleaning [the] kitchen ... Sometimes, when I'm sick and she [the disabled wife] has to go to toilet, my daughters would help me out. And sometimes, when I cannot come out of bed because I'm sick, they will do most of the work at home. (Gujarati Hindu male caring for a wife paralysed after a stroke – FG/IDI)

Support for carers within extended households

Extended households remain a common feature of South Asian communities (Owen 1993, 1994). Many carers in the present study were members of households which comprised elderly parents, married sons, their wives and children, and unmarried sons and daughters. Female carers in extended households included wives, daughters-in-law, unmarried daughters, and occasionally, granddaughters. Male carers were predominantly husbands, or married and unmarried sons.

Support for female carers within extended households

By virtue of their size, extended households contain a large pool of people who could potentially be called upon to support male or female carers. However, in reality, the choice is much more restricted (Twigg & Atkin 1994). Carers' experiences are affected by the complexity of family dynamics and intergenerational differences in expectations of giving and receiving support. Other complicating factors include differences in opinion about the nature of support provided, the value attached to the different types of support, and sensitivity about cross-gender caregiving.

Since physical contact between adult members of the family outside of a marital relationship is prohibited, the support that carers can expect from other female members of the family is severely restricted. For example, daughters-in-law may avoid helping with tasks involving physical contact with their husbands' male relatives, although they may help with practical tasks such as preparing meals, laundry and other household tasks.

Therefore, the presence of other females did not increase the likelihood that appropriate help would be available. One concern for elderly female spouse carers was that, although they were living in joint families, they could only expect limited help from other family members. For instance, the involvement of daughters-in-law with intimate care of a father-in-law was ruled

out on moral grounds and the support from male relatives was unreliable:

My son goes to work and how can my daughter-in-law help? It would be indecent for her. I have to do everything myself ... give him [the disabled husband] a bath, feed him, help him in the toilet and dress him. (Bangladeshi Muslim female caring for husband with diabetes – FG)

In some families, misunderstandings and a mismatch of expectations created tensions, and the lack of support with certain tasks, such as personal care, was construed by carers as an unwillingness to help:

No, there's nobody. My daughter-in-law will do it, but that's if I am in bed, you know, then only she'll do it. (Gujarati Hindu female caring for daughter with mental health problems – FG/IDI)

There are clearly difficulties in striking an appropriate balance between the respective needs of carers and their helpers, which are complicated by notions of rights and obligations, particularly when there is little opportunity for frank and open discussion about managing care.

Most Asian parents have an expectation that their sons and daughters-in-law will look after them in their old age, and if necessary, care for other members of the family. A majority of daughters-in-law in the present study acknowledged that they were obliged to look after their husband's family and accepted that it was 'our duty to care'. However, the needs of female carers were often overlooked by other members of the family, either because they were helping carers in other ways or because they were unwilling to do more. A number of daughters-in-law commented that, although they were more than willing to care for their husband's relative, they found that the lack of emotional support undermined their ability to cope (Ahmad & Atkin 1996). Some felt that the amount of effort and energy they put into caring for their husband's relative, or the difficulties they experienced, were not recognised or appreciated. One such daughter-in-law reported that her mother-in-law refused to accept that she was not coping very well and the help offered by social services was necessary:

... [S]ocial services offered help to give Nanima [the grandmother] a bath twice a week and a night nurse to settle her down at night ... but my mother-in-law, she was not happy. She spoilt her face. She started saying that I was making too much fuss over nothing. She's not prepared to accept that I can't cope. (Gujarati Hindu female caring for her husband's grandmother with dementia – IDI)

The accounts of difficult relationships between mothers-in-law and daughters-in-law are not unique to South Asian communities, and have also been reported in other cultures. However, the stress of caregiving can add further complications to a relationship that is

already strained by differences in status. Therefore, it is not surprising that caregiving within extended households is more stressful than it might at first appear. Evidence from the literature also suggests that caregiving within the extended family is a constant struggle at containment (Bould 1990, Butt & Mirza 1996).

Support for male carers in extended households

The present sample of male carers in extended households included husbands, fathers, and married or unmarried sons. Male carers reported that other members of their family supported them, and to all intents and purposes, female members of the family were either the main carers or contributed equally. Thus, the type of support was dictated by the gender of the relative with disabilities and the availability of appropriate support within the household. For example, male spouse and parental carers reported that they received most personal and practical support from their wives and daughters-in-law. Female members of the household undertook most of the tasks involving personal and practical care:

... [M]y sons' wife is here so it is a little bit easier now. (Pakistani Muslim male caring for two daughters, both with serious visual and speech impairments – FG)

However, where male carers were responsible for a male relative, personal tasks were shared with other male relatives.

The accounts of male carers in extended households were not sufficiently detailed to make an accurate assessment of support from other members of the family. It is possible that because of the gendered nature of caregiving, the nature of the tasks male carers performed were less onerous and the lack of support was less critical than for female carers. However, for male carers who had the sole responsibility of looking after a male relative with disabilities, the lack of support from other family members was hurtful because it was assumed that they could cope on their own. Although very few spoke openly about their difficulties, the male carers most likely to be affected were the ones who were living with the relative with disabilities:

... [B]ecause I have taken the responsibility for my father, they [the siblings] assume I'm capable ... that's my problem. My brothers live somewhere else, but they expect me to do everything. (Pakistani Muslim male caring for an elderly father with dementia – IDI)

Support for carers in female-headed households

The majority of carers in this category were divorced, separated, widowed or unmarried daughters. The experiences of female carers in nuclear and extended households suggest that, although the carers were not entirely

satisfied with the level of support, most believed that the practical or emotional support they did get helped them to cope. The present findings suggest that female carers who were single, widowed or divorced were more likely to be isolated and left without adequate support. For instance, one Gujarati Hindu female carer commented that she was unable to express her fear and concern about her daughter with disabilities after the death of her husband because he was the only person with whom she had been able to share the responsibility:

... [W]hen he [the husband] was alive, he used to say to me, 'Why are you crying? You know I am here, I will help you.' and now, who's going to help? Nobody. (Gujarati Hindu female caring for a daughter with learning difficulties – FG/IDI)

In South Asian communities, widows, or divorced or separated women often find that changes in their personal circumstances have a major impact on their social position. Widowed carers suggested that their life became more difficult since they could not command the respect that their married status had conferred upon them. Older widows bemoaned the fact that their husbands' deaths had left them unsupported and unprotected. Those caring for daughters with disabilities felt particularly vulnerable because, whilst their husbands were alive, they were cushioned from the demands of the outside world, and spared the responsibility of negotiating and managing official business. Older widowed female carers who either did not have sons or had sons who were unwilling to help found it difficult to make important decisions on their own concerning both the care and treatment of their relatives with disabilities, and about financial and household matters. In households without a male relative, the carers' ability to cope is seriously compromised by their sense of helplessness in carrying out everyday practical tasks. The experiences of elderly widows and divorced carers clearly highlight the importance of help with so-called compensatory tasks which may not get overlooked because they are not seen as integral to caregiving:

The house is very cold and ... it's quite damp. If there was a man in the house, he'd be handling things like that ... I don't speak English ... I don't know what to do. (Gujarati Hindu female caring for daughter with epilepsy and mental health problems – FG/IDI)

Discussion

The present paper has discussed the sources, quality and quantity of informal support that was available to carers in the four main South Asian communities. It has also explored the factors which determine access to support in different types of households. The sample of carers was drawn from a variety of religious, linguistic

and socio-economic backgrounds with varying patterns of migration and settlement in the UK. The experiences of carers across the four groups were similar.

The overwhelming impression given by carers, irrespective of gender and ethnic group, was that immediate members of the family were their main source of support. The quality and quantity of this support was determined by family size and structure, and the availability and willingness of family members to assist in caregiving tasks. The age, gender and number of relatives with disabilities needing care, and the nature and complexity of their disablement, determined the level of support that carers needed or expected from others. A majority of carers, particularly in nuclear and female-headed households, were isolated and struggled to provide care without adequate practical and emotional support.

The hidden nature of informal caregiving means that changes in the circumstances of carers and their relative with disabilities often get overlooked. The lack of support can seriously undermine carers' ability to provide care. Carers who are unwell themselves, elderly, lone parents, separated, divorced, widows/widowers or who do not speak English are particularly vulnerable. Changes in the cared-for person's age or condition have implications not only for who in the family provides care, but also for the level of support that they need. The gender of the cared-for person, cultural and individual preferences and expectations, and the availability of practical and financial resources are also important in caring decisions. The extended family provides some support, but this is often sporadic and not always dependable. Children are often used as a resource, especially for language support when accessing services.

Other findings by the present authors, reported elsewhere (Katbamna *et al.* 2002), have also suggested that the problems which carers face are exacerbated by a lack of support from primary healthcare services. Female carers in all four communities generally encountered greater difficulties negotiating and organising support from formal agencies because of language and communication difficulties, and a lack of knowledge about health and social services. Female carers in the Bangladeshi community encountered additional obstacles in seeking and accepting help from informal networks and formal services.

Evidence from the present study broadly reinforces the conclusions of other research, i.e. that South Asian carers as a group are no more likely than carers from other communities to be assured of support from wider kinship and social networks. In fact, the findings challenge the pervasive assumption and stereotype that South Asian people live in self-supporting extended families, and therefore, that the support of the social services is largely unnecessary. Such assumptions can

have a detrimental effect on carers, particularly those who have recently settled in the country, and especially if their opportunity to forge new social network is curtailed by their caregiving role. This was clearly evident in the case of female carers in the Bangladeshi community. Other stereotypes which imply that South Asian people are younger and 'fitter', their needs are not same as those of white people, and that they do not have the same entitlement to resources are equally misleading and harmful (Askham *et al.* 1995, Yee 1995). It is particularly worrying that such negative stereotypes can influence the development and the provision of services for service users in the South Asian communities.

Health and social services have a poor record of supporting users and informal carers. There are general barriers to service receipt experienced by people from minority ethnic communities in the UK. These include the inability of services to meet the needs of users who speak languages other than English, forms of service provision which are culturally inappropriate or inflexible, and attitudinal barriers among service providers which run from a lack of understanding to racism (Atkin *et al.* 1998, Atkin & Ahmad 2000, Katbamna *et al.* 2001).

Services need to better understand the diversity of unpaid caregiving, and avoid both ethnic stereotypes and support models which may be better suited to white carers. The importance of addressing users' and carers' needs in planning and delivering health and social care services has been emphasised in various policy documents from the 1990 NHS and Community Care Act to the White Paper *Modernising Social Services* (Department of Health 1998). The importance of meeting carers' needs for information and support, and help in maintaining their own health has again been emphasised in the National Strategy for Carers (Department of Health 1999a). The provision of support for carers was further strengthened in the Carers and Disabled Children Act 2000, which gives carers a right to an assessment of their own needs and service support, independently of the person they look after (Department of Health 2001a). The National Service Frameworks for older people and mental health both stressed the importance of meeting carers' needs and supporting them in their caring role (Department of Health 1999b, 2001b).

Awareness about carers and their needs is also an issue for health professionals. General practitioners (GPs) and the primary healthcare team can play important roles in supporting users and carers (Twigg & Atkin 1994, Katbamna *et al.* 2001). The GP is the first 'port of call' for the majority of carers. A failure to recognise the carer as such, or having recognised the carer, a failure to refer the carer on to others (in the primary healthcare team or elsewhere) who could provide support, may have far-reaching and potentially costly, consequences. Dealing

with a carer and the person she or he looks after only when a crisis occurs is likely to be far more expensive than recognising and tackling support needs while they are still minimal. This is particularly the case with carers from South Asian communities whose access to knowledge about support and services may be additionally limited in comparison to carers from the majority community.

Acknowledgements

We thank all the carers who took part in focus groups or interviews. The project was funded by the NHS(E) R&D Programme for People with Physical and Complex Disabilities, but any views expressed here are those of the researchers alone.

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