

Supporting South Asian carers and those they care for: the role of the primary health care team

Savita Katbamna, Padma Bhakta, Waqar Ahmad, Richard Baker and Gillian Parker

SUMMARY

Background: Demographic and socioeconomic changes have increased policy interest in informal carers. However, despite the multicultural nature of British society, most research in this field has been in majority communities.

Aim: To explore the role of the primary health care team (PHCT) in supporting carers from British South Asian communities.

Design of study: Qualitative study.

Setting: Four South Asian communities in Leicestershire and West Yorkshire.

Method: Focus groups and in-depth interviews were used to assess male and female carers, supported by a literature review.

Results: Failure to recognise carers' needs, gaps in service provision, and communication and language issues compromised carers' ability to care. While some carers were positive about the PHCT role, the main weaknesses concerned poor consultation, PHCT attitudes towards carers, and access to appropriate services.

Conclusion: South Asian carers' experiences largely parallel those of others, but there are some issues that are distinct, namely, language and communication barriers, culturally inappropriate services, and implicit or explicit racism. The multi-ethnic nature of Great Britain requires that professional practice enhances the ability of minority ethnic communities to provide informal care. The findings underline the important role of the PHCT in ensuring that carers' needs are taken seriously and that appropriate services reach them.

Keywords: ethnic groups; cultural diversity; carers; primary health care team.

Introduction

DEMOGRAPHIC, social, economic, and policy influences have brought informal care and carers to the fore over the past 20 years;^{1,2} however, most research on carers has been with the majority Caucasian population. There are several reasons why informal care and its support are becoming important issues for British South Asian communities.

First, although these communities are relatively young, the population of older people will increase sharply over the next 10 years.³ Secondly, morbidity related to heart disease, digestive and respiratory disorders,⁴ cancer, and levels of limiting long-term illness,^{5,6} are high in these communities. Thirdly, employment patterns for some groups may affect their ability to remain independent in old age,^{7,8} through reduced access to pensions, savings, and contributory benefits. Finally, South Asian family and household structures are changing. Immigration legislation, increased mobility and relocation, housing availability, challenges to marriage patterns, reduced family size, increases in women's labour market participation, and changing expectations, all play a part.⁹ The extended household still exists but it is becoming less common, although the assumption that British South Asian families 'look after their own' remains pervasive.

The primary health care team (PHCT) can play a key role in supporting carers.¹⁰⁻¹² The general practitioner (GP) is the first 'port of call' for most, but failure to recognise the carer or to refer them on to support services may have far-reaching consequences. A White Paper¹³ states that the National Health Service (NHS) should meet locally defined and measured needs in ways that improve equity. Access to care has to be fair 'in relation to people's needs, irrespective of geography, class, ethnicity or sex' [Paragraph 8.5]. The development of services to ensure this level of assistance for South Asian carers has been impeded by a dearth of knowledge.

This study attempts to fill this gap by exploring carers' experiences of the PHCT and how they would like to be supported.¹⁴ The project also developed practice guidelines to help PHCTs¹⁵ and these are reported in a companion paper.¹⁶

Methods

Given the limited knowledge and sensitivity of the subject, a qualitative approach was indicated,¹⁷ initially comprising focus groups followed by in-depth interviews. A series of three single-sex focus groups were arranged for male and female carers from the four main British South Asian communities in Leicestershire and West Yorkshire. A detailed account of the methods is given elsewhere.¹⁴

Topic guides for the focus groups were based on issues

S Katbamna, PhD, research fellow; P Bhakta, BA, RGN, research associate; G Parker, PhD, Hon MFPHM, Nuffield professor of community care, Nuffield Community Care Studies Unit; R Baker, FRCGP, professor of clinical governance, Clinical Governance Research and Development Unit, University of Leicester. W Ahmad, PhD, professor of research in primary care, Nuffield Institute of Health, University of Leeds.

Address for correspondence

Dr Savita Katbamna, Nuffield Community Care Studies Unit, Department of Epidemiology and Public Health, University of Leicester, 22-28 Princess Road West, Leicester LE1 6TP.

Submitted: 13 December 1999; Editor's response: 27 March 2000; final acceptance: 3 September 2001.

©British Journal of General Practice, 2002, 52, 300-305.

HOW THIS FITS IN*What do we know?*

Community care policy for frail elderly and disabled people was conceived to act as a working relationship between formal health and social care services and informal carers. For most carers, the GP is the prime resource on health matters, for themselves and their dependants.

What does this paper add?

Although the needs of South Asian carers are similar to those of white carers, they face additional difficulties negotiating access to primary care services because of language and communication problems, cultural differences, and the negative attitudes of the primary care team towards them.



that arose during community consultation and the evidence from the literature review. The guides were flexible, covering broad issues but also allowing emergent themes to be accommodated. The issues covered were: attitudes towards disability, personal experiences of caring and its impact, carers' experiences of accessing and using primary health care services, and how services might be improved to meet carers' needs. The third focus group checked emergent findings from the first and second groups. Interviews, which were based on focus group findings, explored in more depth the experience of caring, its associated costs and benefits, sources of family and community support, and access to and use of services, but again were flexible enough to accommodate emergent themes.

Extensive community and PHCT liaison, word of mouth, and 'snowballing' were used to encourage carers to identify themselves to the research team. 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 subjects in a wide range of caring relationships; for example, people who were caring for young and adult disabled offspring, parents, spouses, parents-in-law, and grandparents. Carers were aged from 20 years upwards. The ages of those who were being cared for ranged from between two years and 85 years. The carers were responsible for people with physical and/or mental conditions, and in some cases with multiple and complex disabilities. Some carers provided care for more than one person at a time.

Table 1 demonstrates the sample composition in terms of ethnicity, religion, and sex. As this table also shows, some carers took part in both the group discussions and the individual interviews.

Group discussions and interviews were conducted by trained interviewers, who were matched for carers' sex and language. Material was tape-recorded; this was negotiated with carers as part of the recruitment process. Tapes were interpreted into English by the trained interviewers and then transcribed. The researchers checked the transcripts with

the interviewers as a validation process, except for the material in Gujarati, which they were able to validate directly as Gujarati speakers. The framework approach was used for analysis.¹⁸

Ethical committee approval for the study was obtained in both areas.

Results

The needs and experiences of South Asian carers are reported in greater detail elsewhere.^{14,19,20} This paper examines South Asian carers' experiences of PHCTs in the context of carers in the majority community.

For most carers of someone with physical disability or chronic illness, the GP was the prime resource on health matters, both for themselves and for the dependant.¹⁰ Moreover, the concerns of South Asian carers about the level and quality of support from PHCTs were remarkably similar to those reported by white carers,^{10,12,21} but in other respects their experiences diverged significantly.

Access to information

As in the white community,^{12,22,23} the ability of carers to provide appropriate and adequate care is seriously hampered by a general lack of information about the condition of the dependant and the type of care required, e.g. lifting and handling skills, coping with incontinence and dietary requirements, supervision of medical treatment, supervision of relatives with mental health problems, and accessing services. Obtaining relevant information is problematic, because carers did not know 'what it was they did not know until they found it out'.¹⁰

The importance that GPs attach to giving information varies enormously. Not all GPs considered it necessary to share information with carers, leaving many ignorant about the dependant's condition and its implications,²⁴⁻²⁶ even though many carers reported that medical information helped them to cope. If it was problematic for white carers to obtain relevant information from GPs then it was even more so for South Asian carers, given language and communication barriers,^{8,27} especially female carers with no English:

'The problem is that when I take my son to the clinic I cannot speak English. I can't actually ask the questions that I want to ask or I don't know which questions I should be asking so I don't think we're getting the full benefit of the meeting. Sometimes I take my daughter ... she is young and she doesn't want to ask too many questions, she gets embarrassed.' (Bangladeshi Muslim female caring for son with speech and mental health problems.)

Carers' opinions of their relationships with professionals or of their quality of service was based on the professionals' attitude and approach. For example, the ease of access to and the responsiveness of the GPs were regarded by many white carers as the most important elements of a successful relationship.¹² Similarly, South Asian carers valued the time and effort that professionals put in to explaining a dependant's condition and acknowledging their problems as carers. Carers who were housebound or who were not literate

Table 1. Composition of sample in focus groups and individual in-depth interviews.^a

Ethnic group (religion)	Pakistani (Muslim)	Gujarati (Hindu)	Bangladeshi (Muslim)	Punjabi (Sikh)
Maximum number of carers in any focus group				
Female	17	13	15	12
Male	8	8	8	4
Number of in-depth interviews				
Female	6	5	6	5
Male	3	3	3	3

^aFifteen carers took part in both the focus groups and the interviews, 71 carers took part in the focus groups alone, and 19 carers took part in the in-depth interviews alone.

in English were particularly grateful to professionals who delivered supplies to their home, timed home visits to suit their needs, and made a special effort to get information translated into their language.

However, negative experiences with PHCTs were more commonly reported. Three main issues are discussed here: the quality of consultation with the GP; the attitude and behaviour of PHCT members; and access to appropriate services.

Quality of consultation

The literature suggests that carers generally appear low on GPs' lists of priority, and that the issues affecting them are not well understood or taken seriously by GPs.²³ The power differential in doctor-carer encounters and the predominantly medical, rather than social, nature of interactions, contributed to carers' unfavourable assessments of their consultations with their GPs.¹⁰ Indeed, the experiences of South Asian carers from all four groups, particularly of women, suggested that the low opinion of carers' encounters with GPs is widespread. Reasons for dissatisfaction with their GPs included rushed consultations, inadequate or no explanation of the dependant's condition, failure to take the carer's concerns about the dependant seriously, and failure to take carers' own health needs seriously. For example, some felt that the GPs' focus on the patient meant that carers were not consulted or informed. As a consequence, some carers did not fully understand what was wrong with the person they were looking after or how best to help them. South Asian carers who did not speak English, but who were expected to play a major role in care-giving, were excluded from the decision-making process:

'My husband has severe diabetes. When the doctor or the nurse come to our house they only talk with my husband tell him what he should do. They don't talk with me much ... they just ignore me. The nurse came to show my husband how to inject medicine. I was beside my husband but the nurse did not talk to me. They should teach me what I should do ... especially in emergency then I would know what to do.' (Bangladeshi carer.)

A particular issue for carers looking after those with mental health problems was exclusion from the care process. They wanted more information about the dependant's condition, its effects, and how to manage behavioural difficulties.¹⁰ The importance that GPs attached to patient confi-

dentiality meant that many South Asian and, indeed, Caucasian carers,^{25,26,28} were left to manage behavioural problems at great expense to their own wellbeing:

'Now my own health is deteriorating and it's becoming impossible to look after him. He doesn't sleep all night. I don't get to sleep at all. I sit here and there, I don't sleep, if I nod off he wakes me up.' (Punjabi Sikh female caring for an adult son with physical and mental health problems.)

Attitude of PHCT members

Attitudes of GPs towards carers vary widely and are influenced first by their own life experiences, particularly values and beliefs about care-giving, and second by GPs' professional training. Older GPs, whose training had a greater emphasis on medical rather than social aspects of care, tend to make assumptions about issues affecting carers,¹⁰ and this had unfortunate consequences for many carers. Younger GPs appear to be more aware of carers' needs. Carers reported that they were perceived by GPs as a nuisance and that they were made to feel uncomfortable for wasting their time, a claim which many white carers have also made.^{12,24} Receptionists were also criticised, being seen as a barrier to access to the GP:

'My little girl had a heart operation last year. It was very difficult, because I had no 'phone, and she fell ill. It was snowing ... I had to walk all the way, carrying my daughter to the surgery. When I got there, the secretary sent me back home, saying, "Make an appointment over the 'phone, and then come back." Believe me, I came home crying.' (Pakistani Muslim female carer.)

The reasons for this are not obvious, but they seem to reflect a lack of understanding of carers' circumstances. GPs have a greater expectation that women, rather than men, will care for a disabled relative.^{29,30} The experiences of South Asian carers suggested that such assumptions and other cultural stereotypes influenced the attitudes and behaviour of GPs towards them. While the GPs' expectations of women in the South Asian groups were no different from those of white carers, male carers in the South Asian groups were not extended the same level of sensitivity as was shown towards male carers in the white community. This is illustrated by this account of a Gujarati male caring for his mother with severe arthritis and depression:

'We had no help or advice from our GP. My mother could not do anything herself. I had to do everything — clothe her, bath her and feed her. I was not married at the time ... it was getting very embarrassing. I had to get married in the end.'

In some cases, the GPs' lack of sensitivity and understanding could be interpreted as a form of implicit or explicit racism. For example, the assumptions that some GPs made about the connection between consanguineous marriages and congenital malformations in children was hurtful for carers:

'... the first thing he asks is, "Is it a first cousin marriage? You've had one disabled child, then another". He's a good doctor but, because of his attitude, I only go when I really have to. I feel embarrassed or ashamed almost. I feel that they must wonder what kind of system Pakistani people have, or that we don't have any sense.' (Pakistani Muslim woman caring for a daughter with a physical disability.)

Having a GP from the same community did not necessarily improve communication, because differentials in power remained between professionals and their patients. Asian GPs' attitudes towards carers were also apparently influenced by their notion of compulsory altruism and family-based care, as traditionally practised in the Indian subcontinent. Carers outlined how Asian GPs believed that it was a carer's moral duty to look after a disabled relative:

'When I saw my GP I told him, "Look, I am just sick and tired, I can't cope anymore". I asked him to give me some medicine. He just joked and said to me: "You are still young, you have no problem, you can look after your husband". He never offered me any help.' (Bangladeshi wife caring for a husband with severe diabetes and a heart condition.)

Access to appropriate services

The most important factors with regard to access to services were the failure to refer patients on and the poor access to services within the PHCT itself.^{26,31} GPs have a very poor record of referring carers to district nurses, who are entirely dependent on the GP or the hospital for referrals.¹⁰ Some carers did receive services, but referrals and direction to other appropriate agencies seemed random. In several cases, in all four groups, there was a clear need for a service but no referral had taken place. Access to occupational therapy, physiotherapy, community nursing, speech therapy, bathing assistance, and home care services, was particularly problematic.

Carers knew little about the composition of the PHCT or what services might be available to them. Some were not even fully aware of the role of the GP. Of course, not knowing what might be available made it impossible for them to ask. A Punjabi Sikh woman was caring for her father-in-law, who had prostate cancer and severe continence problems, about which his GP knew. She eventually managed to get incontinence pads through the health centre, but only after a relative in another town had mentioned that such things

were available. Unfortunately, this problem is not peculiar to South Asian carers, as others have highlighted similar variations in the level and quality of the incontinence service.^{10,32}

Sometimes the failure of GPs to respond to need seemed to be related to their ignorance about the services available, either within the primary care arena or elsewhere; for example, with regard to incontinence supplies and speech therapy. Some non-responsiveness was owing to differences in the professionals' and carers' agendas. One particular tension was focused around offering to train carers to do tasks that they had done for some time but which they no longer felt able or willing to carry out. An elderly Gujarati man who had been caring single-handedly for his wife over many years explained:

'My own health has not been good and I had asked for some help to bath my wife and for domestic help. They offered to train me how I could do it myself. I told them that I have been doing that for the past twenty-three years and I can't do it any more now that my health is bad.'

Other carers preferred to do without services because they feared that their cultural and religious beliefs would not be observed; this was particularly the case for Muslim carers. Some Gujarati Hindu carers, in contrast, accepted support but still found staff lacking in cultural knowledge or understanding, as related by a daughter-in-law caring for an elderly grandmother with dementia:

'The nurses don't understand our culture ... they think my grandmother should wear a jogging suit instead of a sari to make it easier to dress and undress her. It's strange to even suggest that an old lady who has worn a sari all her life should wear jogging pants. Their [the nurses'] values are different from ours. The old lady is confused as it is ... we don't think it right to rob her of her remaining dignity.' (Gujarati daughter-in-law caring for a grandmother with dementia.)

Carers also experienced services that seemed unable to respond flexibly to their needs regardless of cultural issues; for example, 'tucking-in' services that came too early in the day for the relative and thus were rejected; not knowing when, and sometimes if, the community nurse was going to arrive, and therefore being unable to plan the day; or feeling that receiving the service imposed as many burdens as it relieved. A Gujarati Hindu woman pointed out that a bathing service for her mother-in-law gave her little respite because the nurse appeared unable to cope on her own.

Discussion

This study sheds some light on the needs of a wide range of carers from four different British South Asian communities. As qualitative research, it cannot tell us what proportion of such carers have positive or negative experiences, but it is helpful in delineating the issues and offering possible solutions.

The failure to recognise carers' needs, and the gaps in information on services and provision of the same, all compromised the carers' efforts to care for their disabled or dependent relatives. Since community care policy depends

on informal carers, it is vital that carers' own health is not undermined in the process. PHCTs have a crucial role in providing information and facilitating emotional and practical support. While some carers in this study were positive about the PHCT, many aspects of care provision were perceived as inadequate.

Dissatisfaction with GP consultations is a major cause of concern for all carers, regardless of ethnic backgrounds. Primary care professionals' time is costly, of course, but carers' time is also valuable. Moreover, it was the quality of interaction rather than its frequency that caused problems. Recognising carers' needs and concerns during consultation would be in everyone's interests, not least by reducing the need for repeated visits. Ensuring that the wellbeing of carers themselves is maintained helps them to continue caring and providing a high quality service; the PHCT thus has a responsibility to the carer as well as the patient. This is now explicitly recognised in the Department of Health's National Strategy for Carers.³³

Support for carers does not have to involve the GP exclusively. Nurses can work collaboratively with GPs to ensure that carers' needs are regularly reviewed and monitored, thus preventing them from getting 'lost' in the system and, perhaps, averting crises.

PHCTs can play a vital role in providing information and advice, yet this does not always happen. Some carers did not even know what their dependant' medical problems were, and were ignorant of basic services. When services were provided they were sometimes inflexible and unresponsive. Primary care providers need to review the way in which they identify need and deliver services that are in their domain and how they refer on to services beyond PHCT.

Carers' experiences of the PHCT in the white community have highlighted not only the crucial importance of this 'gateway' to, and supplier of, services and support,³⁴ but also the imperfect way in which it operates. A sense of not being taken seriously, lack of advice and information, and poor partnership between carers and professionals, have all been demonstrated.^{10,12,21} In this respect, British South Asian carers are not so different from their counterparts in other communities and any improvement within primary care in support for carers should benefit all communities.

What South Asian carers may experience that other carers do not are the additional language and communication barriers, because of services that are not well informed, culturally sensitive, and which are implicitly or explicitly racist.

All users of primary care are entitled to be dealt with on no other criteria than individual need. Positive action is needed to ensure that services are purposely or deliberately targeted at 'hard to reach' communities. Providing information in a variety of media and languages, 'outreach' work with community groups, and 'carer awareness' initiatives, are all activities that primary care groups and trusts should consider. Ethnic monitoring and equal opportunity policies have made progress in redressing inequalities in the provision of services, but problems remain. All staff in PHCTs need to be trained for work in a multi-ethnic society, and equal opportunities policies need to be in place to combat racism, whether conscious or unconscious, institutional or individual. Such approaches are not optional extras or 'frills'.

Primary care is at the heart of the new NHS; unwillingness or inability to identify and meet the needs of some of its most vulnerable patients and those who care for them is clearly not acceptable.

Development projects have demonstrated how difficult it can be to engage the PHCT with a carers' 'agenda'.^{11,21} Indeed, one project concluded that, without incentives to encourage substantial change in practice, real support for carers would be unlikely to emerge from primary care.²¹ In the second stage of this particular project, work was done with PHCTs to develop GP practice guidelines to help in their work with South Asian carers.^{15,16} Elements of these guidelines would enhance support for both white and South Asian carers, while some are specific to minority ethnic communities. Such guidelines may be a productive way to achieve change, and there is now a need for research to examine their effectiveness in embedding support for carers firmly within primary care.

References

1. Parker G. *With due care and attention: a review of research on informal care*. 2nd edition. London: Family Policy Studies Centre, 1990.
2. Parker G. *Where next for research on carers?* Leicester: Nuffield Community Care Studies Unit, 1994.
3. Owen D. *Ethnic minorities in Britain*. [1991 Census Statistical Papers 1-4.] Warwick: Centre for Research in Ethnic Relations, 1993.
4. Smaje C. *Health, 'race' and ethnicity: making sense of the evidence*. London: King's Fund Institute, 1995.
5. Dunnell K. *Sources and nature of ethnic health data*. London: North East and North West Thames Regional Health Authority, 1993.
6. Charlton J, Wallace M, White I. Long-term illness: results from the 1991 census. *Population Trends* 1994; **75**: 18-25.
7. Oppenheim C. *Poverty: the facts*. London: Child Poverty Action Group, 1990.
8. Modood T, Berthoud R, Lakey J, et al. *Ethnic minorities in Britain: diversity and disadvantage*. London: Policy Studies Institute, 1997.
9. Katbamna S, Bhakta P. *The needs of Asian carers: a selective literature review*. Leicester: Nuffield Community Care Studies Unit, 1997.
10. Twigg J, Atkin K. *Carers perceived: policy and practice in informal care*. Buckingham: Open University Press, 1994.
11. Powell M, Kocher P. *Carers impact: how do we know when we have got there?* London: King's Fund, 1997.
12. Parker G. *With this body: caring and disability in marriage*. Buckingham: Open University Press, 1993.
13. Department of Health. *The new NHS - modern, dependable*. [Cm 3807.] London: HMSO, 1997.
14. Katbamna S, Bhakta P, Parker G, et al. *Experiences and needs of carers from the South Asian communities*. Leicester: Nuffield Community Care Studies Unit, 1998.
15. Katbamna S, Baker R, Parker G. *Guidelines for primary health care teams: South Asian Carers' Project*. Leicester: Nuffield Community Care Studies Unit, 1998.
16. Katbamna S, Baker R, Ahmad W, et al. Development of guidelines to facilitate improved support of South Asian carers by primary health care teams. *Qual Health Care* 2001; **10**(3): 166-172.
17. Walker R. An introduction to applied qualitative research. In: Walker R (ed). *Applied qualitative research*. Aldershot: Gower, 1985.
18. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess B (ed). *Analysing qualitative data*. London: Routledge, 1994.
19. Katbamna S, Bhakta P, Parker G. Perceptions of disability and care-giving relationships in South Asian communities. In: Ahmad, W (ed). *Ethnicity, disability and chronic illness*. Buckingham: Open University Press, 2000.
20. Bhakta P, Katbamna S, Parker G. South Asian carers' experiences of primary health care teams. In: Ahmad, W (ed). *Ethnicity, disability and chronic illness*. Buckingham: Open University Press, 2000.
21. Moffat F. *London Borough of Sutton GP/Carers Project: raising the profile of carers in general practice*. London: Wandsworth Health Authority, 1996.

22. Langan J, Whitfield M, Russell O. Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities. *Health and Social Care*, 1994; **2**: 357-365.
 23. Warner L, Wexler S. *Eight hours a day and taken for granted?* London: The Princess Royal Trust for Carers, 1998.
 24. Glendinning, C. *Unshared care*. London: Routledge & Kegan Paul, 1983.
 25. Levin E, Sinclair I, Gorbach P. *Families, services and confusion in old age*. Aldershot: Gower, 1989.
 26. Sperlinger D, Furst M. The service experiences of people with pre-senile dementia: a study of carers in one London Borough. *Int J Geriatr Psychiatry* 1994; **9**: 47-50.
 27. Matischen G. *Ethnicity and access to primary health care*. Sub-project to West Central Halifax Primary Research Project, 1995.
 28. Aneshensel CA, Pearlin LI, Mullan JT, et al. *Profiles in care-giving: the unexpected career*. London: Academic Press Limited, 1995.
 29. Arber S, Gilbert N, Evandrous M. Gender, household composition and receipt of domiciliary services by elderly disabled people. *J Soc Policy* 1988; **17**(2): 153-175.
 30. Qureshi H, Walker, A. *The caring relationship: elderly people & their families*. Basingstoke: Macmillan Education Ltd, 1989.
 31. Beresford B. *Positively parents: caring for a severely disabled child*. London: HMSO, 1994.
 32. Briggs A, Oliver J. *Caring: experiences of looking after disabled relatives*. London: Routledge and Kegan Paul, 1985.
 33. Department of Health. *Caring about carers: a national strategy for carers*. London: HMSO, 1999.
 34. Yee L, Blunden R. *General practice and carers: scope for change?* London: King's Fund Centre, 1995.
-