Development of guidelines to facilitate improved support of South Asian carers by primary health care teams

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Abstract

Background—Evidence based guidelines are regarded as an appropriate basis for providing effective health care, but few guidelines incorporate the views of users such as carers.

Aim—To develop guidelines to assist primary health care teams (PHCTs) in their work with carers within South Asian communities.

Methods—The guidelines were drawn up by a development group consisting of members of teams in areas with South Asian communities (Leicester and Bradford). The teams were invited to make their recommendations based on a systematic review of literature on minority ethnic carers and the findings of a study of the needs and experiences of local South Asian carers. A grading system was devised to enable the teams and a group of expert peer reviewers to assess the quality of evidence in support of each recommendation.

Results—The teams agreed seven recommendations, graded according to available evidence and strength of opinion. External peer review supported the PHCTs' interpretation of evidence and their recommendations. The recommendations included consideration of communication and information for carers, coordination of care within teams, and recognition by team members of the roles of carers and their cultural and religious beliefs.

Conclusion—There are particular steps that PHCTs can take to improve their support of South Asian carers. It is possible to develop guidelines that take users' views into account and incorporate evidence from qualitative studies.

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Keywords: primary health care; South Asian carers; guidelines

According to the 1991 census, 3% of the British population is made up of people whose roots originated in India, Pakistan and Bangladesh.¹ One of the important features of the British South Asian population is its diversity. Some of the major differences between the four main communities are reflected in their history of migration and settlement patterns, languages, religious and cultural traditions, socioeconomic circumstances, and social support networks.² Evidence also suggests that the level of literacy in English was lower in the

Summary of recommendations

- Members of PHCTs should communicate with carers in a form which carers can understand [a (i)]
- Carers should have access to information about the full range of services offered by the primary health care team [a (iii)]
- Team members should acknowledge the role played by informal carers in providing care for sick and disabled people [a (ii)]
- The team should know which of its patients are carers [b (iii)]
- Members of PHCTs should be aware of the range of services other members of the team are able to offer to carers [a (iii)]
- Carers should be treated as individuals in their own right, their individual needs being recognised with regard to cultural and religious beliefs [a (iii)]
- A basic patient held continuing record should be kept at the disabled person's home to facilitate the coordination of care provided by different health professionals [b (iii)]

Bangladeshi community than in the Indian and Pakistani communities. In all the communities literacy in English was significantly lower among women, particularly those over the age of 50.³

The combination of sociodemographic factors and ease of access to healthcare services has a major impact on the ability of South Asian carers to provide care. Evidence suggests that South Asian carers face particular difficulties in negotiating support from health professionals due to language and communication barriers, differences in cultural and religious beliefs about care giving, and difficulties in accessing appropriate and relevant services.⁴ Practitioners have also reported difficulties in meeting the needs of users in the minority ethnic communities due to language and communication problems, lack of knowledge and understanding about cultural and religious practices, and lack of awareness of the range of services provided by agencies which support carers.⁵ Guidelines may be helpful as a first step in improving care.

There are no generally accepted practice guidelines for primary health care teams (PHCTs) to use when working with any carers, let alone those from minority ethnic communities. The guidelines described here were primarily developed for PHCTs to assist them

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in their work with South Asian carers. However, evidence suggests that in many respects the experiences of carers in the white community⁶⁻⁷ are similar to those in South Asian communities. Indeed, several reports have advocated better support for carers from primary care services.⁸

Guideline development has become increasingly systematic.⁹ Explicit approaches are now used to identify and appraise research evidence before recommendations are formulated and graded according to the strength of evidence.¹⁰ Methods have been developed to enable guideline groups to reach consensus¹¹⁻¹² and procedures are available for assessing guidelines to avoid disseminating those of poor quality.¹³ In the UK a new plan for the NHS¹⁴⁻¹⁵ envisages the use of guidelines by most health professionals and the National Institute for Clinical Excellence (NICE) has been created to oversee guideline development.

One of the main benefits of involving users in guideline development is that it provides opportunities for users' opinions to be incorporated in the formulation of guidelines. However, the participation of users in guideline development remains unusual.¹⁶⁻¹⁸ The involvement of lay users in guideline development groups, traditionally dominated by professionals, is problematic¹⁹⁻²⁰ because lay members may experience difficulty in contributing when the topic is technical and the groups are dominated by health professionals. A number of different methods of involving users in guideline development have been explored, including the use of a consumer advocate, but none has proved entirely satisfactory.²¹ The involvement of non-English speaking users in guideline development also needs consideration. To develop the type of health service envisaged in the current NHS reforms,¹⁴ and to address issues identified in the National Strategy for Carers,²² alternative methods for involving these users need to be investigated.¹⁰

Guideline recommendations that take users' views into account need to draw on non-experimental as well as experimental studies. Furthermore, some guidelines may be applicable to only small numbers of service users, and the organisation of large trials would be impossible. Our aim was to develop guidelines based on the evidence of a systematic review of the literature and a study of South Asian carers to assist PHCTs in their work with carers within South Asian communities.

Methods

LITERATURE REVIEW

A literature review was undertaken to identify methodologically sound studies of the experiences of minority ethnic carers and their needs for support from primary health care services. Medline, EMBASE, and the Social Science Citation Index were searched for relevant publications between 1985 and 1996, supplemented by searches of the Ethnic Health Information Database, the Royal College of Nursing Library Database, and OCLC Article First and Papers First. References in identified texts were also searched. The search terms included

- (i) Well designed studies that included detailed information about techniques for gathering information from more than one source, and the use of appropriate methods of analysis.
- (ii) Well designed studies but limited to a single method or lacking information about the methods of analysis.
- (iii) Studies with weak methods of data collection and/or analysis.

Box 1 Strength of evidence grading.

"Asian", "Asian carers", "informal carers", "race", "culture", "ethnicity", "health services", "primary care", "ethnicity and care giving roles and responsibilities", "male carers", "female carers", "primary health care team", and "community nurses". All relevant studies were non-experimental and were graded into three levels according to their quality (box 1). No randomised trials or experimental studies of interventions to improve the support for South Asian carers were identified. Dual independent assessment of studies was used to apply the quality criteria.

STUDY OF SOUTH ASIAN CARERS

In addition to the systematic review, a study was undertaken to obtain primary evidence of the experiences of South Asian carers of using primary care services.⁴ The study included male and female carers within the Gujarati Hindu, Pakistani and Bangladeshi Muslim, and Punjabi Sikh communities in Leicester and Bradford.⁴ The carers were identified through leaflets in South Asian languages, radio interviews, temples and community organisations, key workers and GP practices, through snowballing, and by personal visits to carers. A purposive sampling was used to select a wide range of caring relationships: people caring for young and adult disabled offspring, parents, spouses, grandparents, and neighbours or friends. Group discussions were facilitated by bilingual facilitators matched for the sex and language of the group concerned. The discussions were tape recorded, translated, and transcribed. Thirty individual interviews with carers, including some who had participated in the discussion groups, explored issues in greater depth for response validation. Carers who participated in the discussion groups and in depth interviews recounted their experiences of primary care services and put forward suggestions for improving services for themselves and those they cared for. Transcripts were analysed by identifying common themes and sub-themes. Each sub-theme was assigned an index to identify relevant sections in the transcripts. The themes and sub-themes were transferred onto charts with interpretation of the results.

DEVELOPMENT OF RECOMMENDATIONS BY PRIMARY HEALTH CARE TEAMS

A guideline development group consisting of seven PHCTs developed the guideline recommendations from the literature review and the findings of the carers' study. The teams were

Box 2 Guideline development methodology.

purposely sampled from the health authority lists of practices in Leicester and Bradford to represent both single handed and group practices, fund holders and non-fund holders, inner city and suburban practices, and those with a high proportion of ethnic minority patients and those with relatively small numbers.

Separate meetings were organised with each participating team. The teams were composed of general practitioners, practice nurses, administrative and reception staff, community nurses, physiotherapists, and social workers. Team members were sent a personal letter of invitation explaining the purpose of the meeting. At the meeting the evidence from the literature review and the findings of the carers' project, including carers' suggestions for improving services, were presented. The team was invited to discuss the findings and suggest possible guideline recommendations. Our approach was designed to ensure that the views of non-English speaking users contributed to guideline development.²³ As the carers were drawn from four different Asian language groups and many of them did not speak English, a member of the research team (SK) acted as the carers' advocate in the guideline development groups and presented their views and the evidence from the literature for improving the quality of support for carers (box 2).

Each team meeting lasted 1–2 hours. The meetings were tape recorded, transcribed, and draft recommendations were extracted. The draft, together with structured assessment forms, were then sent to all members of the participating teams. They were asked whether each recommendation should be included or modified and whether additional recommendations were required. They were also asked to assign a grade to each recommendation (box 3).

The revised guideline recommendations were submitted to 11 external peer reviewers. These were general practitioners and health service managers in Leicester and Bradford selected because of their interest in, or experience of, providing care to South Asian people or because they had expertise in guideline

- A** Strong recommendation: regarded as important with little or no difference in the views of team members.
- B** Moderate recommendation: regarded as relatively less important with some limited difference in the views between team members.
- C** Recommendation regarded as optional.

Box 3 Strength of recommendations grading.

development. They were asked to comment on the content and grading of recommendations. The completed structured assessment forms, including comments and suggestions, were analysed by the research team to check the level of agreement reached in the assessment of the strength of each recommendation and in the assignment of a grade against each recommendation. Each recommendation was assigned two grades: the letter *a* or *b* to indicate the strength of the recommendation made by the guideline development group, and a numeral *i*, *ii* or *iii* to represent the strength of the evidence from the systematic review of literature.

Results

SUMMARY OF LITERATURE REVIEW

Forty eight studies and reports on minority ethnic carers were identified²; 26 were eliminated because of poor quality or because they did not include a relevant ethnic group, leaving 22 for inclusion in the study, although the quality of many of them was poor: 11 were graded level (iii),^{24–34} nine were graded level (ii),^{5 35–42} and two were graded level (i).^{43 44}

STUDY OF SOUTH ASIAN CARERS

One hundred and five carers (72 women, 33 men) aged between 20 and over 65 from the four main South Asian communities took part in the focus groups and in depth interviews. The age of the person being cared for ranged from a two year old to several people in their mid 80s. 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. Their main concerns included the lack of information about health-care services and difficulties in obtaining particular services (a more detailed account of results from the study are described elsewhere⁴⁵). The carers proposed improvements, including provision of comprehensive information about their disabled relative's condition, the composition and roles of members of PHCTs, different services, and ways of improving access to PHCTs and services offered by them. These suggestions formed the scope of the draft guideline recommendations which were fed into the guideline development groups.

The guideline recommendations

- **Members of PHCTs should communicate with carers in a form which carers can understand [a (i)]**

EVIDENCE FROM THE LITERATURE

Studies^{43 44} of Afro-Caribbean and South Asian parents of children with inherited blood disorders suggested that, because of communication problems, many parents did not realise how the condition was transmitted. Consequently, some parents did not find out about the condition until after the birth of a third or fourth affected child. Similar difficulties in dealing with professionals such as GPs, community nurses, or home helps were also reported by Asians caring for their elderly relatives.³⁸

EVIDENCE FROM THE SOUTH ASIAN CARERS PROJECT

The findings of our study suggest that the inability to speak English and read material in their mother tongue was a major problem for many older carers of both sexes, but particularly for women. Carers voiced similar concerns about limited access to information, unsatisfactory consultations with health professionals, and the inadequate provision of interpreting services.

COMMENTS FROM MEMBERS OF PHCT

Team members acknowledged that language and communication problems were major problems. The teams indicated that they had limited resources and the provision of trained interpreters in primary health care was inadequate. Although there was no agreement about who should take responsibility for interpreting services, teams suggested the use of simple terminology, access to trained interpreters, a three way telephone service linking carer, practitioner and interpreter, and a dictionary of key terms in ethnic languages to improve communication. This recommendation was categorised **a (i)** by the teams and their assessment of the wording and grading was verified by the peer reviewers.

- **Carers should have access to information about the full range of services offered by the primary health care team [a (iii)]**

EVIDENCE FROM THE LITERATURE

Due to lack of awareness, the uptake of health and social services by minority ethnic carers and their disabled relatives is generally low.^{36 39} An evaluation of mental health services for minority ethnic users and carers highlights a similar lack of knowledge about services, including specific information about how to care for relatives with mental health problems.⁴⁰

EVIDENCE FROM THE SOUTH ASIAN CARERS PROJECT

Carers in our study suggested that, although they and their disabled relative were in contact with general practitioners, their access to services was limited by lack of awareness about the

composition of the team, the roles and responsibilities of different team members, how to access them, lack of information about the referral system within and outside the team, and lack of awareness about the range of services provided. Poor access to information was not restricted to carers with language problems.

COMMENTS FROM MEMBERS OF PHCT

Team members suggested that surgeries should consider displaying practice photographs of staff together with information about their roles, providing detailed information in the practice booklet or on video or audio tapes, and nominating a member of staff to collate information for carers. This recommendation was supported by level **(iii)** evidence. However, the importance of the issue was reflected in the findings of the South Asian Carers' Project and was recognised by all teams. The final wording and the grading **a (iii)** were supported by the peer reviewers.

- **Team members should acknowledge the role played by informal carers in providing care for sick and disabled people [a (ii)]**

EVIDENCE FROM THE LITERATURE

Health care agencies can fail to recognise the emotional needs of parental carers,⁴³ some parents feeling that, despite experiencing emotional difficulties with their caring role, they received little support from service providers. Similarly, studies of the role of PHCTs^{28 41} revealed that carers expected team members to recognise the importance of their role and include them as "co-workers", with their views, need for support and continuing ability to provide care being taken into consideration.

EVIDENCE FROM THE SOUTH ASIAN CARERS PROJECT

The experiences of South Asian carers confirmed that, although they were responsible for providing care for their disabled relatives and, in many cases, carers were heavily involved in giving round the clock personal and practical support, their own needs for support were rarely recognised.

COMMENTS FROM MEMBERS OF PHCT

Some team members felt that, because of heavy case loads, they were unable to respond to carers' adequately. There was disagreement about the benefits of carer support groups because of organisational difficulties in meeting the needs of carers from different cultural and linguistic backgrounds and different caring responsibilities. However, many practitioners recognised that carers needed their support and recommended the use of checklists to assess carers' needs, acknowledging carers as individuals with their own needs, and to ensure that service managers give higher priority to meeting these needs. This recommendation was supported by level **ii** evidence. As the findings were supported by

the evidence from the South Asian Carers' Project and the issue was regarded as important by teams, the recommendation was graded **a (ii)**. The peer reviewers supported this recommendation.

• **The team should know which of its patients are carers [b (iii)]**

EVIDENCE FROM THE LITERATURE

Two recent studies^{41 46} highlighted the importance for carers that professionals should recognise their roles as carers and that they should be treated as individuals in their own right. Identification and registration of carers in practices were recommended as important for developing services for carers. Although these two studies did not include carers from the South Asian community, their recommendations have implications for South Asian carers.

EVIDENCE FROM THE SOUTH ASIAN CARERS' PROJECT

When carers in our study were asked to suggest ways in which their own needs might be met in future, many indicated that they would like their practice to set up a register for carers including some information about the nature of their caring role.

COMMENTS FROM MEMBERS OF PHCT

Team members indicated that most were in favour of a practice register for carers. However, some inner city practices with limited resources were concerned about the cost of maintaining a register. Some practitioners also expressed concern about striking a balance between meeting the needs of carers and maintaining the confidentiality of their disabled clients. This recommendation was supported by evidence in category level **iii**. However, the issue was found to be important in the South Asian Carers' Project and was accepted as important by teams. The wording of the recommendation was changed from "The practice should have a register of carers" to "The teams should know which of its patients are carers" on the advice of the peer reviewers and it was graded as **b (iii)**.

• **Members of PHCTs should be aware of the range of services other members of the team are able to offer to carers [a (iii)]**

EVIDENCE FROM THE LITERATURE

An evaluation of service support to parents of children with sickle cell or thalassaemia disorders⁴³ revealed poor awareness of haemoglobinopathies among staff, and GPs' involvement with children and parents was limited. Other studies^{41 46} reported similar findings and advocated improved communication between health and social services to facilitate joint planning.

Similar problems were noted by researchers investigating the effectiveness of mental health services.⁴⁰ They reported that GPs and other team members were gateways to other services, and whether or not they made referrals

was determined by the attitude and knowledge of the practitioners concerned. A low referral rate to counselling services or voluntary organisations was a reflection of lack of knowledge about other services among the health workers.

EVIDENCE FROM THE SOUTH ASIAN CARERS' PROJECT

The findings of our study indicated that, for many carers, their contact with health professionals was restricted to their GP. In many cases carers were not referred to other practitioners either within or outside the team.

COMMENTS FROM MEMBERS OF PHCT

Many team members acknowledged they were not aware of the services available for carers, and lack of information made it difficult for them to make appropriate referrals. The quality of other relevant research evidence was limited, but teams agreed the issue was important and suggested that teams should have systems for communicating information about their own roles and how they may be contacted. This recommendation was supported by evidence in category level **iii**. Evidence from the South Asian Carers' Project confirmed that carers often had difficulties obtaining access to services. The peer reviewers were in agreement with the teams' assessment and the recommendation was graded **a (iii)**.

• **Carers should be treated as individuals in their own right, their individual needs being recognised with regard to cultural and religious beliefs [a (iii)]**

EVIDENCE FROM THE LITERATURE

The findings of studies^{36 39} suggested that South Asian carers were concerned that many services including day care, respite, and domiciliary services were insensitive to their cultural and religious requirements. Consequently, many carers were reluctant to encourage their disabled relatives to use these services.

EVIDENCE FROM THE SOUTH ASIAN CARERS' PROJECT

These views were echoed by carers in our study who reported similar concerns about the lack of appropriate services for their disabled relatives.

COMMENTS FROM MEMBERS OF PHCT

Although there was strong agreement about the importance of recognising carers as individuals in their own right and being sensitive to cultural and religious beliefs, some team members were uncertain about the role of training in improving cultural awareness. This recommendation was supported by evidence in category level **iii**. Teams recognised this problem, but were unsure of the most appropriate response. The peer reviewers agreed with the teams' assessment and the recommendation was graded **a (iii)**.

- **A basic patient held continuing record should be kept at the disabled person's home to facilitate the coordination of care provided by different health professionals [b (iii)]**

EVIDENCE FROM THE LITERATURE

Relevant research evidence was limited, although patient held records have been used in other circumstances and been acceptable to patients.⁴⁷

EVIDENCE FROM THE SOUTH ASIAN CARERS' PROJECT

Carers indicated that having a record at home would facilitate communication between them, the patient, and health professionals and reduce the need to repeat the clinical history to professionals.

COMMENTS FROM MEMBERS OF PHCT

There was support from community nurses for patient held records at home, and many nurses were already using them. This recommendation was supported by evidence in category level **iii**. Findings of the South Asian Carers' Project provided some support for this recommendation and it was generally accepted by teams. The reviewers also suggested rewording to include information about nursing care. The wording of the recommendation was modified and graded **b (iii)**.

Discussion

The literature from the majority white community suggests that PHCTs have a key part to play in supporting carers.^{6,7} The GP is the first "port of call" for the majority of carers, and the GP and PHCT have roles in both the identification and the support of carers.⁸ Many South Asian carers reported that the lack of recognition of their own needs, gaps in service provision, and communication and language difficulties compromised their efforts in providing care for their disabled relatives. Similar concerns about the lack of support for carers and recommendations to primary care services to respond have also been highlighted in the Department of Health's National Strategy for Carers.²²

The guidelines highlight the need for PHCTs to recognise the particular needs of South Asian carers. These include the provision of information in a form that can be understood, and assessment of carers to identify their need for additional support. However, this attitude is not fully reflected in the recommendations made by the teams. The limited scope of the guideline recommendations, and the low ranking of some of them, may be explained by lack of evidence and the unwillingness of teams to embrace more comprehensive recommendations.

The teams who contributed to the development of the guidelines acknowledged the problems faced by carers and were able to suggest practical responses. However, the teams also stressed the importance of collaboration with community trusts or health authorities—for example, in the provision of an interpreter

service or the introduction of a carer held record. Those health authorities or primary care groups that have a relatively high population of South Asian patients should develop policies to enable PHCT to meet the needs of these carers.

The carers in our study reported several failures and PHCTs accepted these criticisms. There appears to be a gap between aspirations to meet carers' needs and actual practice. We hope these guidelines will help teams, primary care groups, and health authorities to close that gap and improve the quality of support offered to South Asian carers. Indeed, many of these guideline recommendations—apart from language, cultural, and religious specific recommendations—can be applied to support all carers, irrespective of ethnic background.

The combination of community consultation and research literature as a way of involving users in guideline development has been suggested previously¹⁷ but there is growing interest in methods for involving users in guideline development. Different models have been attempted but none has proved entirely satisfactory.²¹ Our approach was a little different^{10,48} and useful for involving those who would not otherwise be included. It offers a model for future research in this field.

The recommendations are concerned with the characteristics of services necessary to meet Asian carers' needs and preferences and do not consider the cost effectiveness of different methods for meeting these needs. Relevant experimental evidence from randomised controlled trials was not available and, because of the very small numbers of carers from the South Asian community, it is unlikely that trials will be undertaken in future. The potential users of the guidelines should note that evidence of this type was not used as the basis for formulating the recommendations, and the grading system was not comparable to other grading systems.^{48,49}

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