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Access to Health Care for Carers: Barriers and Interventions

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

December 2003

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Contents

Acknowledgements 4

Executive Summary

Background 5
Objectives of the study 5
Research methods: literature review 6
Research methods: consultation 6
Typology of barriers to access to health care for carers 7
Key findings 7
Gaps and weaknesses in the evidence base 11
Recommendations for further research 12
Dissemination 13

The Report

Chapter 1 Introduction 14
1.1 Access to health care 14
1.2 Carers and care giving 15
1.3 Policy context 17
1.4 Aims and objectives of study 18
1.5 Structure of the report 19

Chapter 2 Research methods 20
2.1 Introduction 20
2.2 The review protocol 20
2.3 References retrieved 28
2.4 Consultation 31
2.5 Data synthesis 32

Chapter 3 Barriers to carers' access to health care 33
3.1 Introduction 33
3.2 Typology of barriers to access to health care for carers 33
3.3 Nature and organisation of evidence 34
3.4 Barriers related to professional characteristics 40
3.5 Barriers related to service issues 45
3.6 Barriers related to language or cultural issues 50
3.7 Barriers related to carer or care recipient characteristics 54
3.8 Barriers related to knowledge and information issues 58
3.9 Conclusion 61

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Chapter 4 Interventions to improve accessibility for carers 63
4.1 Introduction 63
4.2 Current policy and practice in the NHS 63
4.3 Interventions to overcome barriers to health care for carers 66
4.4 Overcoming barriers related to professional characteristics 70
4.5 Overcoming barriers related to service issues 72
4.6 Overcoming barriers related to language or cultural issues 74
4.7 Overcoming barriers related to carer or care recipient characteristics 75
4.8 Overcoming barriers related to information and knowledge issues 77
4.9 Conclusion 79

Chapter 5 Discussion and conclusions 82
5.1 Introduction 82
5.2 Summary of results 82
5.3 Conceptualising access to health care for carers 85
5.4 Recommendations to improve carers' access to health care 90
5.5 Gaps and weaknesses in the evidence base 94
5.6 Recommendations for further research 99
5.7 Dissemination and implementation of research findings 102

References 103

Appendices

Appendix 1 Electronic search strategies 110

Appendix 2 Results of databases searched 124

Appendix 3 Data extraction form 125

Appendix 4 National and local organisations consulted 128

Appendix 5 Interview schedule for national organisations 129

Appendix 6 Interview schedule for local organisations 131

Appendix 7 Summary of core studies 133

Appendix 8 Summary of intermediate studies 136

Appendix 9 Summary of supplementary studies 139

Appendix 10 Summary of respite studies 141

Appendix 11 Summary of intervention evaluations 146

Appendix 12 Summary of local interventions 152

Acknowledgements

The research was funded by the NHS Service Delivery & Organisation (SDO) Research and Development Programme (Project reference SDO/24/2002).

We are grateful to all those individuals who contributed their time and expertise to the consultation.

Colleagues have provided helpful advice and support during the course of the work, in particular Karen Croucher, Michael Hirst, Emily Holzhausen, Lisa O'Malley and Julie Williams. Emese Mayhew's contribution to the early stages of the review was invaluable. We are grateful to librarians in the J.B. Morrell Library at the University of York for all their assistance. Sally Pulleyn provided valuable secretarial support throughout the study.

Sally Baldwin died tragically during the course of the work. It goes without saying how much we all miss her. Sally was a key member of the research team, and we greatly valued her input to the project.

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Executive Summary

Background

The General Household Survey 2000 shows that approximately 6.8 million adults in Britain provide care to sick or disabled relatives or friends, or the elderly. Carers report high levels of stress, anxiety and depression, as well as general health problems and physical injuries such as strained backs associated with lifting. The more demanding care, the less likely it is that carers will have time to attend to their own health care needs. Current government policy puts an emphasis on supporting carers in their caring role, and ensuring that the NHS and social services helps them maintain their health. The intention that carers obtain quality health care services is not necessarily realised in practice. Many carers feel marginalised by health care professionals and believe that their own needs for health care are overlooked. Consequently, it is important to identify the barriers that prevent carers from accessing, and utilising, effective health care services, as well as interventions that can improve accessibility.

Objectives of the study

The overall aim of the work was to inform the NHS Service Delivery and Organisation (SDO) R & D Programme about the theory and evidence on carers' access to health care. The two key objectives were:

- to examine the evidence from UK and international research (published and unpublished) in order to identify:
  - the problems and barriers that carers experience in accessing health care services, and any associated issues relating to equity of access and level of unmet need
  - evidence of interventions designed to improve carers' access to health care services, and how these vary according to age and circumstances
- to consult with key stakeholders with an interest in carers' access to health care about the findings from the review and recommendations for further research.

The following report documents key themes from the literature review and consultation. In addition, it presents a typology of barriers that carers encounter when accessing health care, and develops a model of access to health care specifically for carers. Detailed information about the interventions reviewed can be found in the supplementary report: *Access to Health Care for Carers: Intervention Evaluations*.

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Research methods: literature review

A protocol was drawn up to guide the review process. The aim of the literature review was to identify all studies published since 1987 that could help answer the central research question: 'What does the research evidence tell us about what restricts, what promotes and what improves carers' access to health care services?' Searches were made of key electronic databases and the Internet. Other search strategies included hand searching, searching web sites of key organisations, and contacting key researchers in the field. Bibliographies of studies were checked to ensure referenced studies were included. Of the 8775 initial references, 46 were found to be both applicable to the research question and of sufficient quality to enter the review; 32 of the reports discussed barriers to carers' access to health care or respite services. The remaining 14 were evaluations of interventions designed to improve accessibility. There were three groups of interventions: primary care initiatives, home-based health care projects, and geographical information systems (GIS) software. The 46 research reports were classified in terms of type of study design and strength of evidence. Some of the studies were stronger and more robust in comparison with others which had implications for the conclusions that could reasonably be drawn. Relevant data were extracted from each study and synthesised through a narrative review.

Research methods: consultation

Contributors to the consultation included policymakers and practitioners with an interest in carers' access to health care. Two main stakeholder groups were involved:

- national statutory and voluntary sector organisations (n=12)
- local organisations that had introduced interventions specifically to improve carers' access to health care (n=8).

Key aims of the consultation were:

- to explore perceptions of the barriers that carers confront when trying to gain access to health care services
- to identify specific examples of interventions, good practice and areas of the country that have made progress in facilitating access for carers
- to complement the review findings, and help make recommendations that are more relevant to those working in the field and using services.

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Typology of barriers to access to health care for carers

Existing conceptual frameworks to help understand why people may or may not gain access to health care did not easily accommodate the particular barriers that carers confront. A typology of barriers, based on existing models and the evidence from the literature review, was developed specifically for carers. It provided the organising framework for examining access to health care for carers, and comprised five different types of barriers relating to:

- professional characteristics
- service issues
- language or cultural issues
- carer or care recipient characteristics
- information and knowledge issues.

Key findings

Barriers related to professional characteristics

Key barriers identified in the literature review and consultation relating to professional characteristics included: lack of recognition of the caring role and awareness of the needs and issues involved; professional uncertainty about roles and boundaries; reactive rather than proactive approaches; prioritising the care recipient at the expense of the carer; professional models, conceptualisations or stereotypes of carers that may not be conducive to meeting their needs.

These are difficult issues to address, especially on a short-term basis. In terms of interventions, the evidence indicated that carer support workers in primary care initiatives provided training and helped raise awareness of carers' issues. This could help deter professionals from allowing preconceived notions and assumptions about carers to stand in the way of referrals or the offer of particular treatments. Health care professionals taking on the role of 'champions' could help to change attitudes and spread good practice. Building up good relationships between carers and professionals, and treating carers as 'partners' in the provision of care, could also facilitate access for carers.

Based on the findings, recommendations to address barriers relating to professional characteristics include: pre- and post-registration training for all health professionals and front-line staff to ensure they identify and accept carers as a discrete group with their own special health needs, and adopt carer-sensitive practices as an integral part of routine patient care; ongoing training to include changes to policy and practice initiatives and/or legislative

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requirements; incentives for primary care professionals to focus on carers' health and proactively offer health checks.

Barriers related to service issues

With regard to service issues, the literature review and consultation consistently identified the following barriers: GP surgeries not identifying carers and/or 'tagging' carers' records; lack of training in carers' issues; 'gate-keeping'; inflexible appointment systems; waiting times; transport and car parking; costs.

With reference to interventions to overcome service issue barriers, a main feature of all primary care initiatives was to set in place systems to identify carers, and tag medical records. There was evidence that home-based interventions helped tackle transport and/or substitute care problems; carers who were housebound or lived in rural areas also gained. Massage therapists, for example, took their tables to carers' homes. Telephone- and computer-based services provided direct access, on demand, to information, education and 'in-home' support groups thereby facilitating easier access to professional support. Geographical information systems software had the potential to inform future developments relating to local provision of services to support carers. Contributors to the consultation emphasised the use of non-health venues, flexibility and simple referral procedures (including self-referral).

Based on the findings, recommendations to address barriers relating to service issues include: identification and tagging of carers in medical records, including hospital admission and discharge notes; inclusion of questions to identify carers in hospital admission and discharge notes; inclusion of a carer question at new patient registration, on regular over-75s' health checks and other standard health screenings, and on repeat prescription forms; provision of health care services in settings which are accessible and acceptable to carers; lowering the threshold of access to services to allow more early, preventive work with carers; identification of a point of contact or carer support worker in each practice or service; greater recognition of the needs and special circumstances of carers in the way in which appointments and services are offered and elective procedures are arranged; more strategic and co-ordinated use of the Carers Special Grant; increase in the local availability of flexible and appropriate respite services; funding for the evaluation of local initiatives to enable them to demonstrate their effectiveness; and recognition and addressing of the transport needs of carers, especially in rural areas, which could include more use of home visits.

Barriers related to language or cultural issues

Language and cultural barriers identified by the literature review and consultation included: carers not being able to speak English; inadequacies in translation and interpreting services; racial prejudice and stereotyping; professionals' lack of knowledge about cultural and religious practices.

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Although no interventions were found that specifically addressed barriers related to language or cultural issues, the importance of reaching out to black and ethnic minority carers was commented upon. The consultation suggested that health professionals with a positive approach to minority carers could encourage access.

Based on the findings, recommendations to address barriers relating to language or cultural issues include: assistance with reading, writing and form completion; expansion of professional interpreting and translation services within practices and services; cultural diversity training for health care professionals in cultural and religious issues and appropriate practices.

Barriers related to carer or care recipient characteristics

The evidence indicated that key barriers relating to the characteristics, behaviours and beliefs of carers or care recipients that served to inhibit access to health care included: carers' approach to care giving and/or health promotion; carers; help-seeking behaviours; personal and/or cultural beliefs and preferences; care recipients' attitude.

The review of the evaluations of interventions showed that many carers accepted their situation and/or did not identify themselves as carers, emphasising the importance, noted earlier, of GP surgeries identifying (and recording) carers. Carers were offered information and support by intermediaries, for example receptionists, which helped overcome their lack of assertiveness. Carer support workers not only provided information but also advocacy services, enabling carers to talk through issues and identify solutions with an independent person. Support groups reduced feelings of isolation, increased confidence and influenced help-seeking behaviour. For carers unable to join conventional support groups, telephone- and computer-based projects offering 'in-home' support groups were valuable. Such interventions were especially useful to carers who valued anonymity, and/or were embarrassed or lacked self-confidence to talk openly. Contributors to the consultation emphasised the value of adopting a holistic approach to carers, aimed at addressing their emotional, psychological and spiritual needs.

Based on the findings, recommendations to address barriers relating to carer or care recipient characteristics include: education for carers by health professionals and/or carer support workers about the benefits of health promotion behaviours and regular screening; reinforcement of recognition of the caring role through discussions with professionals, proactive provision of information, and promotion of services for carers; and promotion of positive images of carers and disability, for example through personal, health and social education courses, or citizenship programmes, in schools and the wider media.

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Barriers related to information and knowledge issues

The following barriers related to information and knowledge issues were uncovered by the literature review and consultation: carers not being given information about available services and how to access them; medical confidentiality.

The evidence indicated that primary care initiatives and telephone- and computer-based projects helped address these barriers. Primary care initiatives, for example, developed information packs and directories of national and local carer support facilities to be used by both carers and health care professionals. Carer support workers also pointed carers in the direction of relevant agencies, and provided advocacy and benefit advice. Telephone- and computer-based interventions were useful in providing carers with information and education. Research showed that carers who were inexperienced could nonetheless be quickly trained to use computer-based systems; in one study, the average age of carers was 68 years. Telephone groups were found to be as effective in providing access to information as on-site groups for rural and/or isolated carers. They also proved cost-effective in supporting rural carers. Contributors suggested that services that were well networked themselves were in a good position to signpost carers to relevant agencies.

Based on the findings, recommendations to address information and knowledge issues include: introduction of initiatives and procedures designed to overcome professionals' concerns about medical confidentiality issues; provision for carers of medical information and current information about available services in a variety of languages and media; and access for health care professionals to up-to-date information on national and local services to assist carers.

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Gaps and weaknesses in the evidence base

Gaps

The study identified clear gaps in the literature in relation to carers' access to: hospital-based care; tertiary services; continuing access from primary to secondary care; national screening programmes; chiropody; dental services; and optical care.

Research has concentrated on services and interventions aimed specifically at carers. Little is known about the impact on carers of generic services designed to improve access for all patient groups, such as: NHS Direct; NHS Direct online; Walk-In Centres; Healthy Living Centres; Advanced Access in primary care; and the National Booking Programme.

The literature review did not uncover any research that looked at health care access in relation to the following groups: young carers; older carers; black and ethnic minority carers; carers from refugee and asylum-seeking communities; rural carers; and carers of people with stigmatising conditions (e.g. mental health, alcohol or drug-related problems; HIV/AIDS).

In comparative terms, the evidence base relating to how language or cultural issues could create barriers, and in turn how these could be overcome, was particularly weak.

Methodological and quality issues

Study designs

Most of the studies included in the review drew on evidence that was cross-sectional and that provided snapshots of the phenomenon under investigation at one point in time by way of either survey or qualitative interviews. There was a deficit of prospective studies with long-term follow-up, collecting qualitative and quantitative data and capturing process and outcomes information. Study weaknesses included: small sample sizes; carer and care recipient views that were not distinguished from one another; failure to disaggregate information about health care services and social care services; and limited analysis of the audit and statistical elements of interventions. Very few studies included an economic component.

Theoretical frameworks and outcome measures

Only a minority of studies were grounded in any sort of theoretical framework about access to health care. Likewise, few studies used standard outcome measures to try to assess changes in health outcomes relating to improved access. Measuring the effectiveness of interventions such as primary care initiatives is particularly challenging, and there is a need to obtain consensus

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from all groups of professionals about appropriate outcomes to demonstrate their effectiveness and cost-effectiveness.

Reporting

There were instances of poor abstracts and reporting on research methods and data analysis. These sorts of inadequacies make the review process difficult, especially in relation to quality control issues.

Recommendations for further research

On the basis of the literature review and consultation, studies should be commissioned that investigate:

- *carers' access to health care in their own right* – more work is needed that focuses on this area, and that does not confuse issues in relation to the health care needs of carers and those of the care recipient
- *carers' access to health care in different setting* – further research should look at carers' experiences and views about access to health care in settings other than primary care; such research should evaluate the specific health outcomes of helping carers to access health care, and look at the impact of introducing special measures that address access problems for carers
- *carers' use of generic NHS services* – there is a need to investigate carers' use of generic services, such as NHS Direct, NHS Direct online; Walk-In Centres; Healthy Living Centres; Advanced Access in primary care; and the National Booking Programme
- *local primary care initiatives* – local primary care initiatives need to be rigorously evaluated, in particular from the point of view of determining long-term effectiveness, and developing transferable and/or sustainable approaches; there is scope for studies aimed at finding out whether these sorts of initiatives help overcome obstacles faced by particular carer groups, for instance young carers
- *culturally sensitive services* – research should be undertaken to find out what it means to have 'culturally sensitive' health care services for carers and how such services can be implemented
- *information and communication technology*. – detailed qualitative information about carers' use of the Internet and e-technologies is needed to inform the development of local, national and international e-health web sites for carers.; research exploring the scope for local primary care initiatives, GP surgeries, hospitals and carers' organisations to jointly provide information on local, regional and national services for carers would also be useful
- *specific carer groups*. – comparative data showing variations between geographical areas and among different groups of carers would be valuable.; research to examine the access experiences of carers of people

with stigmatising conditions is needed, as is research into the special problems of access in rural areas

- *carers from refugee and asylum-seeking communities.* – research is required that examines access to health care services for carers from refugee and asylum seeking communities
- *outcome measures*. – research to reach agreement among different professional groups about appropriate outcome measures to gauge the effectiveness of interventions to improve access would be valuable
- *economic evaluations* – economic evaluations, especially of interventions to improve access for carers, would be valuable to policymakers to know the financial implications of initiatives, and how much difference they might make
- *conceptual frameworks* – it would be valuable to undertake further work to bring together different conceptual models and frameworks into a more coherent framework for conceptualising access for carers more broadly.; the value of the model should then be tested empirically.

Dissemination

Continued efforts should be made to disseminate research findings as widely as possible, making use of the full range of communication and media channels.

The Report

Chapter 1 Introduction

1.1 Access to health care

In the White Paper, *The New NHS: Modern, Dependable*, the government sets out a vision in which local health communities work in partnership to plan and deliver improvements in health care services to benefit the community as a whole (Department of Health, 1997). The needs of patients are central; people are to be offered prompt high-quality treatment and care when and where they need it. The NHS Plan to modernise the NHS reinforces these themes (Department of Health, 2000a). Two of the Plan's core principles are that 'The NHS will shape its services around the needs and preferences of individual patients, their families and their carers' (p.4; paragraph 3) and that 'The NHS will respond to different needs of different populations' (p.4; paragraph 4). To help realise this vision, new generic services such as NHS Direct, NHS Direct online, Walk-In Centres, the National Booking Programme and 'Advanced Access' in primary care have been introduced, initiatives that have the potential to improve accessibility to health care for all patient groups.

Optimal access to health care has been defined as 'providing the right service at the right time in the right place' (Rogers *et al.*, 1999). However, while recent NHS policies (Department of Health, 1997, 2000a) emphasise the provision of equitable health services to the whole population of England, obtaining the right support at the right time does not depend solely on the availability of health care services. Gulliford *et al.* (2001) distinguish between 'having access', which is when there is an adequate supply of services and systems in place to facilitate utilisation, and 'gaining access', which relates to entry to, or actual utilisation of, services. Even where adequate services do exist, issues relating to affordability, physical accessibility and acceptability can limit the extent to which patients and carers make use of them; social or cultural obstacles can also restrict utilisation (Gulliford *et al.*, 2001). Interactions between structural variables such as ethnicity or poverty may intensify access problems. Gulliford *et al.* (2001) also point out that barriers to access can occur at different points on the health care pathway from initial contact, to entry and utilisation of effective, appropriate and acceptable services, through to the attainment of the desired or appropriate outcomes.

The Independent Inquiry into Inequalities in Health found that individuals and communities most at risk of ill health tended to experience the least satisfactory access to the full range of preventive services (Acheson, 1998). Inequity in access to services is not restricted to social class and geography.

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For example, people from black and ethnic minority communities are less likely to receive the services they need.

1.2 Carers and care giving

Informal carers of ill and disabled people, and the elderly, are another group that is vulnerable to exclusion from health and social care services (Becker, 2000; Howard, 2001), in part because they are isolated from the rest of society as their caring duties tie them to their homes. There is no simple definition of the term 'carer', but generally speaking it refers to the provision of unpaid care, help or support to a relative or friend who cannot manage on their own because they suffer from physical disabilities or mental health problems, or difficulties related to old age (Maher and Green, 2002). This (informal) support enables the care recipient to continue to live in his or her own home. As far as personal care is concerned, carers may provide assistance in moving, handling, feeding, personal hygiene and administering medication (Princess Royal Trust for Carers, 2003). Carers can be male or female, of any age, culture and religion (National Assembly for Wales, 2000); they may combine caring with full- or part-time work (Princess Royal Trust for Carers, 2003). For the purposes of this report, we are focusing on issues relating to those carers who provide unpaid care, help or support to another person who cannot manage on their own because of illness, frailty or disability. In other words, our working definition of carer does not include parents with childcare responsibilities (unless they are caring for disabled children who place demands on them beyond those required of parents of non-disabled children), 'formal' carers who provide paid care, or carers who are involved in care giving on a voluntary basis for a charitable or voluntary organisation.

As indicated above, there is great diversity among carers, both in terms of their own characteristics and the characteristics of those whom they support (Eley, 2003). From this point of view, it is misleading to talk about carers as though all carers were alike (see, for example, Eley, 2003). Analysis of the 2000 General Household Survey (GHS) shows there are approximately 6.8 million adults in Britain providing care to individuals with a range of physical and mental conditions (Maher and Green, 2002). Of these, nearly one in 20 (4 per cent) spend 20 or more hours per week providing care. According to the GHS, 18 per cent of carers in Britain are women, compared with 14 per cent who are men. Caring responsibilities increase with age from 8 per cent of 16–29 year olds to a peak of 24 per cent among those in the 45–64 age group; this figure then decreases to 16 per cent for those aged 65 and over. Three per cent of adults care for two or more people. Sixty-two per cent of carers surveyed said they were looking after someone with a physical disability, 6 per cent looked after someone with a mental health disability and a further 18 per cent looked after someone with both a mental and physical disability. The remaining carers (14 per cent) said that the person they cared for needed help because of the results of ageing. The GHS analysis shows that 26 per cent of carers in Britain are working full time, and 19 per cent part time. Among people of working age, the economically inactive are the most likely to be carers – the Survey showed that 21 per cent were looking after someone compared with 13 per cent of

full-time workers, 17 per cent of part-time workers and 15 per cent of the unemployed.

Half of those providing care for 20 hours a week or more reported a long-standing illness, and just over one-third (35 per cent) said their illness limited their activities. Elderly carers in particular reported health problems (47 per cent reported a limiting long-standing illness). Carers looking after someone who lived with them were more likely than those caring for someone living elsewhere to report health problems arising from their responsibilities (59 per cent compared with 29 per cent).

A substantial body of literature now exists showing that carers believe caring has adverse effects on their own physical and emotional health. For example, carers report high levels of stress, anxiety and depression, general health problems, loneliness and social isolation, as well as physical injuries such as strained backs associated with lifting (Parker, 1993; Twigg and Atkin, 1994; Warner, 1995; Brown and Mulley, 1997; Henwood, 1998; Arksey *et al.*, 2000; Keeley and Clarke, 2002). Nearly 40 per cent of carers taking part in the GHS for 2000 reported that their physical or mental health had been affected as a result of caring (Maher and Green, 2002). However, establishing a causal relationship between caring and ill health in general is problematic (Parker and Lawton, 1994). Recent work in the Social Policy Research Unit (Hirst, 2000) based on secondary analysis of the British Household Panel Survey reveals that caring has greater impact on carers' emotional health rather than physical health, especially for carers who provide 20 or more hours of care per week.

The work by Hirst (2000) also shows that the health of carers is more likely to deteriorate than improve over time compared with health changes in non-carers. This might reflect the fact that almost half the carers responding to a large-scale questionnaire survey by the Princess Royal Trust for Carers reported that caring left them no time to look after their own health (Keeley and Clarke, 2002), findings that have been reported elsewhere (Cunningham and Dick, 1995; Rogers *et al.*, 1998). Research shows that the more demanding the care is, the less likely it is that carers will have time to seek help in relation to their own health (Acton, 2002). 'Symptom containment' can be a feature of the pressing need to fulfil the routine tasks associated with care and domestic work (Rogers *et al.*, 1998).

It is known that carers' help-seeking activities involve actively engaging with: informal and formal 'mediators' (Cotrell and Engel, 1998; Rogers *et al.*, 1998); community pharmacists (Harris *et al.*, 1998); professionals involved with care recipients, such as day hospital staff (Walder, 1995); telephone advice lines (Mahoney *et al.*, 2001); and computer-based services providing information and 'in-home' support groups (Gallienne *et al.*, 1993; Magnusson *et al.*, 2002). These studies confirm evidence pointing to the importance of the social network in carers' help-seeking behaviours, with professional help being sought last (Czuchta and McCay, 2001). While carers may not seek professional help immediately, they are nevertheless more likely to make additional use of primary health care services both during and after the care-giving episode (Hirst, 2000).

1.3 Policy context

The closure of long-stay hospitals and the growing pressure to support people within their own homes or in the community has led to increasing government reliance on informal care provided within the family (Stalker, 2003). Care in the community has raised the profile of unpaid, family caring; family caring is not new, but making it central to government policy focuses a spotlight on it (Brechin *et al.*, 2003).

In recognition of the important contribution carers make to society, the last ten years has witnessed a growing emphasis on supporting carers in their caring role. This is important because recent trends indicate that more individuals are likely to be heavily involved in providing longer periods of care (Hirst and Hutton, 2000). During a typical life span, six out of ten individuals are likely to assume 'heavy' caring responsibilities (20 hours or more per week) at some point in their lives (Hirst and Hutton, 2000). The government is committed to ensuring that the NHS and Social Services should help carers maintain their health (Department of Health, 1999a). In 1999, the government published its national strategy for carers, *Caring about Carers* (Department of Health, 1999a). The strategy identifies information, support and care as crucial to carers. It addresses the possibility that carers might neglect their own health because they are focusing on the care they provide rather than on the care they might need themselves. It states that 'Carers have a right to see their own health needs met. They need help to maintain their own health, both physical and emotional' (Department of Health, 1999a: 55). The Carers Special Grant, ring-fenced monies that local authorities can apply for, aims to stimulate the provision of innovative respite care and short breaks to give carers time out from caring.

More recently, the Carers and Disabled Children Act 2000 strengthened carers' rights under the Carers (Recognition and Services) Act 1995 to an assessment of their own ability to provide care where they provide (or intend to provide) substantial amounts of care on a regular basis. The practice guidance to the new Act emphasises the key role that GPs and other primary care staff play in supporting carers (Department of Health, 2000b). Standard Two of the National Service Framework for Older People stresses the importance of good information for carers, pointing out that without information carers are more likely to suffer from stress and consequently be less able to continue to care (Department of Health, 2001).

The Electronic Patient Record now being discussed is the likely vehicle to take forward the government's commitment to the identification of carers by GP surgeries, originally stipulated in the National Priorities Guidance (Department of Health, 1998). There is now a performance target in the new General Medical Services (GMS) Contract that comes into force in April 2004 which would award a general practice a further three points if they initiated carer identification and a mechanism for the referral of carers for social services assessment.

The intention that carers obtain quality primary, secondary and specialist health care services is not necessarily realised in practice. Recent research into carers' experiences of the NHS suggests that although carers are in regular touch with the NHS and value the recognition and support they receive, many still feel 'ignored and invisible' and that their own needs for health care are overlooked (Henwood, 1998).

Given how vital good health care is for carers, it is important to identify obstacles that stand in the way of carers accessing and utilising effective services. To this end, the NHS Service Delivery and Organisation (SDO) Research and Development Programme commissioned research into the problems and barriers to access to health care for carers, and effective interventions to remedy variations. The research team was led by the Social Policy Research Unit (SPRU) at the University of York, working in conjunction with the primary and community care consultancy Acton.Shapiro. This report presents the study findings.

1.4 Aims and objectives of study

The overall aim of the study was to inform the SDO programme about theory and evidence on carers' access to health care. Underpinning this aim were two key objectives:

- to examine the evidence from UK and international research (published and unpublished) in order to identify:
  - the problems and barriers which carers experience in accessing health care services (including health promoting and preventive services), and any associated issues relating to equity of access and level of unmet need
  - evidence of specific, practical and effective interventions that can improve carers' access to health care services, and how these approaches vary according to the carer's age and circumstances.
- to consult with key stakeholders, notably carers' groups, major voluntary organisations and national and local statutory bodies with an interest in access to health care, about both the findings from the literature review and recommendations for further research.

This report documents both the findings from the literature review and the consultation. We included a total of 46 primary studies and reports in the review; of these, 32 identified barriers to health care for carers while the remaining 14 comprised evaluations of interventions designed to overcome these obstacles. As will be seen, common themes and issues emerged from the review and the consultation exercise. Based on the evidence from the review and the accounts collected during the consultation, we provide insights into the areas where there are gaps in knowledge, comment on the strength of the evidence base, make recommendations for future research and suggest strategies to improve accessibility for carers. We further develop the schematic diagram by Gulliford *et al*. (2001) of issues in access to health care included in the original scoping study on access commissioned by SDO. The

refined version shows additional issues specifically relating to access to health care for carers.

1.5 Structure of the report

The report is organised as follows.

- Chapter 2 discusses the methods adopted for the literature review and consultation respectively.
- Chapter 3 documents the evidence from the literature review and the consultation about obstacles to carers' access to primary care, hospital-based care, screening programmes, respite care and short breaks. It makes a start on presenting ideas about practical solutions and remedial action to improve access for carers.
- Chapter 4 presents the findings from the review of the literature and the consultations about interventions aimed at helping carers gain access to health care. The range of interventions comprises: primary care initiatives; community-based initiatives; home-based health care projects (telephone- and computer-based technologies and complementary therapies); and geographical information systems (GIS) software.
- Chapter 5 draws together the findings from the literature review and consultation, as a preliminary to: developing a model showing access issues specifically relating to carers; presenting strategies to facilitate carers' access to health care; identifying gaps and weaknesses in the evidence base; and making suggestions for future research priorities.

Chapter 2 Research methods

2.1 Introduction

A thorough literature review was conducted with advance decisions made about how the literature would be found, appraised and collated. A protocol guided the review process, which aimed to minimise bias in the presentation of the findings, and ensure that our intentions were transparent and explicit. This chapter sets out how the studies presented were chosen for inclusion in the review. It reports on the various stages of the process, from defining the question, searching for evidence, applying the inclusion criteria, appraising the strength of the evidence and synthesising the findings of the final selection of studies. It also sets out how the complementary consultation exercise was conducted.

2.2 The review protocol

2.2.1 The question

The review question was 'What does the research evidence tell us about what restricts, what promotes and what improves carers' access to health care services?' The review team spent time developing an understanding of the question as it informed each stage of the review process. The focus was on carers' access to services that are provided in any setting and directly address their own physical and mental health needs as individuals, which may or may not relate to their role as a carers. These services may promote the health of carers or play a role in preventing their ill health. It was anticipated that clear boundaries around the literature would not always be possible, so intertwined is the person's role as a carer with their own needs. The review team however worked on the basis that, for example, studies focusing on access to services that provided education to the carer on correct lifting techniques to prevent back injuries would be included, but studies examining access to those services providing training in the correct insertion of catheter tubes for the care recipient would not. Within this, it is acknowledged that lack of information about the care recipient's health and circumstances and how to manage the care provided adds to carer stress and contributes to carers' ill health (Department of Health, 1999a).

The emphasis on research evidence in the literature review aimed to establish what the available best evidence could tell us about the issue, compared to the experiential and anecdotal knowledge of the policymakers and practitioners consulted in the field. Gaps and weaknesses in the evidence base could thus be identified. The review aimed to determine the barriers that restrict access to health care, to find good evidence of interventions that had potential to overcome these barriers and to locate robust evaluations of projects that had been demonstrated to improve access. In the event, the review reports research evidence on the barriers to access, and interventions that indicate

possible solutions, since there is a paucity of rigorous evidence demonstrating positive health-related outcomes.

2.2.2 Search strategy

Research evidence was identified using a number of channels, shown in Table 2.1.

Table 2.1 Identifying research

- Searches of appropriate electronic databases
- Reference checking of articles retrieved
- Searching for publications of key authors
- Citation searching on Social Science Citation Index (SSCI)
- Checking relevant Internet sites
- Consultation with key national and local organisations
- Contact with key researchers in the field
- Contacting lead researchers identified from the National Research Register
- Consulting specialist libraries
- Open request for references on JISCMail sites
- Hand searching of journals (Medical Journal of Australia, Health and Social Care in the Community, Journal of Public Health Medicine)

The review team included an information scientist from the Centre for Reviews and Dissemination (CRD) who was instrumental in developing the electronic search strategies. The following databases were searched for references for relevant studies with a range of keywords and search strategies.

CD-ROM databases

- Cochrane Controlled Trials Register (CCTR)
- Cochrane Database of Systematic Reviews (CDSR)
- National Research Register (NRR)

Databases on SilverPlatter

- British Nursing Index (BNI)
- CINAHL
- EMBASE
- Health Management Information Consortium (HMIC) (HELMIS, DHdata and the King's Fund databases)
- MEDLINE and PREMEDLINE
- System for Information on Grey Literature in Europe (SIGLE)
- Sociological Abstracts

Free web databases

- Caredata – http://www.elsc.org.uk/bases_floor/caredata.htm
- Database of Abstracts of Reviews of Effectiveness (DARE) http://agatha.york.ac.uk/welcome.htm
- Health Technology Assessment Database (HTA) http://agatha.york.ac.uk/welcome.htm
- NHS Economic Evaluation Database (NHS EED) http://agatha.york.ac.uk/welcome.htm
- Social, Psychological, Educational and Criminological Trials Register (SPECTRE) – http://128.91.198.137/

Subscription-only web databases

- Planex – http://www.planex.ndirect.co.uk/validate2.asp?url=/default.asp

Databases on BIDS

- PsychINFO – http://www.bids.ac.uk/
- International Bibliography of the Social Sciences (IBSS) – http://www.bids.ac.uk/

Databases on Web of Science

- Social Science Citation Index (SSCI) – http://wos.mimas.ac.uk/

Databases on OVID Web

- Allied and Complementary Medicine Database (AMED) – http://gateway.uk.ovid.com/

Details of the search strategies for each of the databases are given in Appendix 1 and the number of records retrieved from each database in Appendix 2. The electronic databases searched aimed to represent literature from both the health and social care domains. Databases were also chosen to provide evidence from published journals, grey literature and ongoing research projects. No language restrictions were placed on the literature searches; however, a date restriction was placed of 1987 onwards. The intention was to capture documents leading up to the introduction of the National Health Service and Community Care Act 1990, in the UK. It was realised that this Act would have no significance in the international literature, although 15 years was also felt sufficient to locate studies relating to current policy, practices and societal norms.

Table 2.2 Internet sites searched

Health Development Agency	http://www.hda-online.org.uk/
Carers UK	www.carersonline.org.uk,
Department of Health Carers site	http://www.carers.gov.uk/
Carers National Association Northern Ireland	http://www.carersni.org/support.html
Princess Royal Trust for Carers	www.carers.org
Contact-a-Family	www.cafamily.org.uk
Crossroads	www.crossroads.org.uk,
Alzheimers Society	www.alzheimers.org.uk
National Primary Care Development Team	www.ndpt.org
National Primary Care Research and Development Centre	www.npcrdc.man.ac.uk
Primary Care at the Department of Health	www.doh.gov.uk/pricare/index.htm
Royal College of General Practitioners	www.rcgp.org.uk/
Royal College of Nursing	www.rcn.org.uk
HAZnet	www.haznet.org.uk
Doctor Patient Partnership	www.dpp.org.uk
Children's Society	http://www.the-childrens-society.org.uk/
Mental After Care Association (MACA)	http://www.maca.org.uk/intro.htm
Making Space	http://www.makingspace.co.uk/
Rethink	http://www.rethink.org/
Health Care for Carers	www.healthcareforcarers.co.uk

Relevant Internet sites, displayed in Table 2.2, were searched and provided empirical material and reports that served as useful background information. The references of all literature received were checked for citations that had not appeared in our initial reference set. Key researchers in the field, subscribers to online discussion boards, and the local and national organisations contacted in the consultation exercise were asked to identify relevant research reports. This proved useful in identifying some additional studies, especially local evaluations of projects, and aided the identification of interventions for the local consultation. The King's Fund library was also visited to obtain documents and source supplementary references, in addition to their database being searched. Citation searches were carried out on SSCI for a handful of key references.

Reference Manager was used to administer the reference set and record decisions made regarding each report.

2.2.3 Study selection

There were three stages for a study to go through before it was included in the final literature review:

- a check for potential relevance, so that only articles were ordered that had the potential to answer the review question
- a check that the review inclusion criteria had been met, so that the study provided direct evidence to address the questions posed
- a check for quality, to ensure that the research findings were generally sound.

Two reviewers scanned the total references to check for potential relevance, double-checking the initial 15 per cent to ensure consistency in decision-making. Where the abstract or title indicated that it related broadly to carers and health services, the report was obtained. If it was not possible to ascertain the study's potential value to the review from the title or abstract, the article was still retrieved and decisions made on the full text. Many references were clearly not appropriate and had been brought forward because of the soft nature of the terms used in social care, but the quality of abstracting on some databases was poor, meaning additional resources were employed in obtaining studies when structured abstracts would have produced more accurate initial decisions.

Two reviewers then checked all of the retrieved studies against the inclusion criteria presented in Table 2.3. Of these decisions, 80 per cent were double checked to ensure that the research studies were eligible for inclusion. The criteria were found useful in placing boundaries around literature that focused on answering the review question, and ensured consistent application across the members of the team. Any disagreements regarding these decisions were resolved consensually in the wider team.

International studies were retrieved and assessed for relevance to the UK health care system. Studies that addressed aspects of Medicare or MediAid in the United States, for example, or rural health issues in developing countries, were not put forward for review. Those that addressed universal issues of access to health for carers in developed countries were put forward. While no restrictions were placed on the search, translating non-English language studies was beyond the scope of this review, although we are aware of the bias this may introduce into the reported findings. Very few foreign-language references were produced, but it remains unknown whether they may have affected the findings of the review.

Once the initial inclusion criteria had been established the studies had to be evaluated in terms of research quality. The review team established the strength of the evidence after examining the research design and the conduct of the methods as outlined in the next section.

Table 2.3 Study selection criteria

Inclusion criteria	Exclusion criteria
Population of interest	
Studies focus on any carers (parents of disabled children, young carers, adult carers)	Studies concerned with the care recipient, or the carer in their care-giving role, where the beneficiary of the intervention is said to be the care recipient
Dimensions of access	
Studies include information relating to any of the dimensions of access to health service interventions	Studies that include evaluations of the health service intervention but fail to address issues relating to access to the intervention in question
Types of interventions	
Studies relate to interventions provided in any setting, that directly address carers' own physical or mental health needs as an individual, which may or may not relate to their role as a carer	Studies that do not address carers' own needs for health services
Geographical coverage	
Studies set in any country if the nature of the study or intervention could be transferable to the UK health care system	Studies conducted in another country where the nature of the study or intervention could not be transferred to the UK health care system because of substantially different funding issues or culture, for example
Language	
Studies in the English language	Studies not published in English
Period of interest	
Studies published from 1987 onwards	Studies published prior to 1987
Study design (see Section 2.2.4)	
• Studies include empirical evidence from experimental or observational research including qualitative research from categories A or B. It may be published or unpublished work • Systematic literature reviews permitted • Should empirical work as outlined above not be available, the review will report separately on other forms of 'evidence' from the typology of study designs (see Table 2.5)	Unsystematic literature reviews, book reviews, discursive/opinion pieces, management audits; in addition, in cases where there are multiple publications from a single study, only the main base report or findings will be used
Quality Appraisal (see Section 2.2.4)	
Included studies meet all five essential elements of the appraisal criteria to secure internal validity of the study and trustworthy findings	Studies that do not meet the essential elements of the quality appraisal criteria, and so may not have trustworthy findings

2.2.4 Strength of evidence

It is important that the conclusions and recommendations of the present report are based on the best evidence available, but this does not mean reporting only 'ideal type' research. Empirical studies were chosen in which the research design and its conduct could be assumed to offer a reasonable level of confidence in the results. These decisions ensured the studies met a basic quality threshold, and that the studies were designed in such a way as to represent good research inquiry.

A quality criteria tool developed by Croucher *et al.* (2003) was chosen to establish whether a study met the quality threshold. There is little consensus over the use of appraisal tools in reviews, and this tool was adopted because reviewer and readers alike can readily understand it; it includes guidance on its practical application and is not resource intensive. The set of criteria is presented in Table 2.4. One reviewer applied these criteria to each study that met the inclusion criteria and those that met the 'essential' elements were put forward for the final review. A second reviewer checked 20 per cent of these decisions.

Table 2.4 Quality criteria appraisal tool

1	Question	Is the research question clear?	E
2	Theoretical perspective	Is the theoretical or ideological perspective of the author (or funder) explicit, and has this influenced the study design, methods or research findings?	D
3	Study design	Is the study design appropriate to answer the question?	E
4	Context	Is the context or setting adequately described?	D
5	Sampling	(Qualitative) Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population?	E
6	Data collection	Is the data collection adequately described and rigorously conducted to ensure confidence in the findings?	E
7	Data analysis	Is there evidence that the data analysis was rigorously conducted to ensure confidence in the findings?	E
8	Reflexivity	Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?	D
9	Generalisability	Do any claims to generalisability follow logically, theoretically and statistically from the data?	D
10	Ethics	Have ethical issues been addressed and confidentiality respected?	D*

E= Essential, D= Desirable

* In some sensitive fields, ethical approval and considerations may be essential.

Source: Croucher et al., *2003*

All research studies that entered the review were then classified using a typology of study design (Table 2.5 below) adapted from that used in the National Service Framework for Older People (Department of Health, 2001). This provided an indication of what type of evidence informed the findings presented. It was intended that research from categories A and B would be included in the final reviewed articles because they were the most rigorous studies, unless other studies were able to fill gaps found in the evidence base. The use of C1 type evidence was used to explore gaps relating to the barriers faced by different types of carers, and in the reporting of interventions, due to the lack of more rigorous research in these areas.

It was appropriate to review different types of research to inform the set of questions guiding this review. The study typology classification was attractive, because of its recognition of the value of good qualitative studies. However, it was found that consideration of the strength that a certain study design can offer should relate to the particular question and line of inquiry. Studies perceived to hold greater internal validity may have less external validity, so reducing their utility to the review. For example, 'treatment' groups in experimental studies were provided with specific interventions (such as computer-based technology or home-based massage treatments) designed specifically for that particular study. Conclusions from these studies, although precise, can limit their relationship with current practice. Also, the transferability of the studies from an experimental setting to a natural one may pose problems. Studies with large convenience samples may be wholly appropriate, when the cost and time taken to glean a random sample of carers from general omnibus surveys is taken into account, providing the researchers reflect upon this issue and note how any bias may relate to the research question. The study design classification was therefore used mainly as a typology rather than a hierarchy of study designs, but even so it remained difficult to operationalise. At least two reviewers, therefore, independently checked the study codes of all research that entered the final review.

Table 2.5 Typology of study designs

Evidence from empirical research and other professional literature	
Evidence type code	***Examples of study type***
A1	Systematic reviews which include at least one randomised controlled trial (RCT) (e.g. Systematic Reviews from Cochrane or Centre for Reviews and Dissemination)
A2	Other systematic and high-quality reviews which synthesise references
B1	Individual RCTs
B2	Individual non-randomised, experimental/intervention studies
B3	Individual non-experimental studies, controlled statistically if appropriate; includes studies using case control, longitudinal, cohort, matched pairs, or cross-sectional random sample methodologies, and sound qualitative studies; analytical studies including secondary analysis
C1	Descriptive and other research or evaluation not in B
Evidence from expert opinion (in the absence of empirical research evidence)	
Evidence type code	***Examples of study type***
C2	Case studies and examples of good practice
D	Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified
E	Professional opinion based on practice, or reports of committees
U	User opinion from carers or carers organisations

Source: adapted from National Service Framework for Older People (Department of Health, 2001)

An Access database was used to manage data extraction forms, presented in Appendix 3. The database recorded a uniform set of information for each study that met the inclusion criteria. All reviewers used the data extraction form to ensure consistency and ease of comparison between studies. The extraction of the substantive content of the studies was based around the barriers that hindered access to health care and the possible solutions and interventions designed to overcome these. It was important to consider the applicability of interventions to other settings, and so evidence relating to an intervention's structure, process and outcomes was extracted with a view to identifying the strengths and weaknesses of the interventions (Wagner and Guild, 1989).

2.3 References retrieved

Table 2.6 shows the number of studies retrieved at each stage of the review, broken down by source of reference. However, we need to sound a note of caution in that it is difficult to compare bibliographic databases. This reflects their variation in size and quality, the different interfaces not enabling the same search strategy to be used on each database, the differing topic areas covered by the databases and the order in which duplication took place.

The search process produced 8775 references. Once duplicate references were removed, 5523 studies remained and some 338 of these were found to be generally relevant to the review. Of these, 69 passed the inclusion criteria; 46 of these met the quality threshold; 36 and 10 studies respectively were categorised as presenting B-type and C-type evidence according to the typology of study designs (Table 2.5). There were no studies containing A-type evidence.

We felt that the findings of the remaining 23 studies, concentrated in the C1 and C2 categories, were insufficiently trustworthy. There were a variety of reasons to explain why they were excluded. For instance, there were examples of poorly focused studies that were unclear about what research questions were being asked, which in turn cast doubt on the appropriateness of the research methods and study sample. In some cases, the rigour with which the research had been conducted was questionable. There was an instance, for example, where researchers identified large discrepancies in (quantitative) data collected by study participants. Authors themselves reported weaknesses in studies, for example problems when conducting interviews; the dynamics of focus groups inhibiting some participants from expressing their views; running out of time and not being able to complete all the interviews planned; small and/or unrepresentative sample sizes. In other studies, it was not evident how the analysis had been carried out; few, if any, details were included and it was unclear whether all of the data had been included in the analysis, or whether the researchers had been selective. Some accounts were summaries of primary research reports written by a third party, who in turn selected what to include and what to exclude (often, details about research methods) in the account, a process which led to questions about the authority of the work. Efforts to obtain the primary reports were generally unsuccessful; any we did manage to obtain were entered into the review process independently. Other articles were reports of early findings from studies still to be completed.

Of the 46 studies included in the final review, 32 discussed barriers to health care for carers and are reported on in Chapter 3. The remaining 14 comprised evaluation studies of interventions and are the focus of Chapter 4.

Table 2.6 Source of references per each stage of the literature review

Databases / source	Received	After de-duplication	Potentially relevant	Passed inclusion criteria	Passed quality criteria	Categorisation (according to the typology of study designs)		
						A	B	C
Peer-reviewed journal databases								
CDSR	11	3	0	0	0	0	0	0
Bibliographic databases								
Health								
AMED	358	195	6	2	1	0	0	1
BNI	192	80	4	1	1	0	1	0
CCTR	56	33	2	0	0	0	0	0
Cinahl	1086	740	63	10	6	0	5	1
EMBASE	1430	1180	25	4	2	0	2	0
HMIC	1729	1080	77	10	8	0	7	1
MEDLINE/PREMEDLINE	1098	610	34	6	4	0	3	1
DARE	27	0	0	0	0	0	0	0
HTA	12	0	0	0	0	0	0	0
NHS EED	4	0	0	0	0	0	0	0
Social care								
Caredata	354	76	21	4	3	0	2	1
PsychInfo	835	501	18	2	2	0	2	0
SocAbs	443	286	10	0	0	0	0	0
SSCI	435	293	16	4	3	0	3	0
IBSS	79	0	0	0	0	0	0	0
SPECTR	34	28	0	0	0	0	0	0
Grey literature databases								
PLANEX	300	82	5	2	1	0	0	1
SIGLE	59	39	3	1	1	0	1	0
Research Registers								
NRR	233	233	10	1	1	0	1	0
Other sources								
Hand searching named journals		n/a	0	0	0	0	0	0
Personal communication		n/a	40	22	16	10	0	6	4
Reference checking		n/a	23	21	5	3	0	3	0
Organisational Internet sites		n/a	0	0	0	0	0	0	0
Specialist libraries		n/a	1	1	1	0	0	0	0
Totals		**8,775**	**5,523**	**338**	**69**	**46**	**0**	**36**	**10**

2.4 Consultation

The consultation situated the evidence from the literature review within current thinking among policymakers and practitioners with an interest in carers and how best to improve their access to health care. The consultation aimed:

- to explore the perceptions of the interviewees on the problems and barriers carers face in gaining access to health care services
- to canvass their ideas on the ways in which carers' access to health care could be improved
- to understand what research, knowledge or information would be most useful to the interviewees in their own work
- to identify specific examples of interventions, good practice and areas of the country that have made particular progress in facilitating carers' access to heath care
- to direct the review team to grey literature relevant to the review
- to set the context for examining the gaps in the literature, and inform how the findings of the review are relevant to the current policy and practice in the NHS
- to complement the findings from the literature review and help to make the recommendations more relevant to those working in the field and using services.

The consultation phase of the study involved two main groups of stakeholders.

- National statutory and voluntary sector organisations including: national carers' organisations; national organisations with a strong interest in, or representation from one or more groups of, carers; and national bodies with an interest in improving access to health care. Twelve organisations were consulted, listed in Appendix 4. The purpose of these interviews was to increase our understanding of how access to health care for carers is conceptualised, and how the barriers are perceived. These interviews also provided the lead into local organisations (see below).
- A small number of local organisations that had introduced new initiatives to improve access to health care for carers. These organisations were identified using the research team's existing knowledge and networks, findings from research and suggestions drawn from the interviews with the national statutory and voluntary bodies. Interviews were held with staff from eight local interventions, the details of which are also summarised in Appendix 4. These interviews focused more on developing our understanding of how certain interventions can reduce or overcome the barriers to access to health care for carers.

Both sets of interviews helped to link the findings from the literature review to current policy initiatives.

The consultation was conducted through prearranged telephone interviews with representatives from these bodies. Agreements were made in advance as

to the most appropriate person to speak to, and the most convenient time and date for the interview. Interview schedules (see Appendices 5 and 6) were drawn up for each of the two groups and sent in advance to the interviewees, together with a brief description of the research project. Whenever possible, potential interviewees were also sent a 'letter of introduction' from the SDO. Detailed notes were taken during the interview and typed up using a common template, to facilitate analysis.

2.5 Data synthesis

The initial findings from the consultation helped us to conceptualise the barriers to access to health care for carers. We set these findings alongside the findings from the literature review to inform our thinking about the development of a typology of barriers. Once finalised, this provided the organisational framework for reporting the evidence from the review and consultation; the typology is contained in the next chapter (Box 3.1). The full analysis of the material from the consultation was then structured around this agreed typology.

A narrative account of the barriers to health care and interventions to improve accessibility is provided, since there was great heterogeneity in the study designs and outputs recorded. The accounts of contributors to the consultation are presented alongside the findings of the literature review, to assist with the interpretation of the research evidence.

Having set out the research methods adopted for the study, Chapter 3 reviews the evidence obtained from the literature review and the consultation on barriers to health care for carers. This leads, in Chapter 4, into a report on the findings relating to the different types of interventions designed to help improve accessibility.

Chapter 3 Barriers to carers' access to health care

3.1 Introduction

This chapter documents what we found about the obstacles that carers confront when trying to access health care. We draw on material from the 32 studies (out of 46) that identified barriers, as well as the accounts of contributors to the consultation. Our starting point is to present a typology of five different kinds of barrier; we use this typology throughout the rest of the report as our analytic framework for discussing the evidence. After presenting the evidence relating to each of the five barriers, we conclude the chapter by commenting on the evidence base before identifying additional barriers that carers face, over and above those experienced by patients in general.

3.2 Typology of barriers to access to health care for carers

Over the years, the concept of access has generated a considerable literature (Andersen and Newman, 1973; Penchansky and Thomas, 1981; Andersen, 1995; Field and Briggs, 2001; Gulliford *et al*., 2001). Different authors in health care research have disaggregated the concept of access into different dimensions that can then be examined separately, and for which operational measures might be developed. Penchansky and Thomas (1981), for instance, proposed a taxonomic definition of access that contained five dimensions:

- availability (whether a service is provided)
- accessibility (whether clients can physically reach the service)
- accommodation (whether the service is organised in such a way that it accommodates clients' needs)
- affordability (whether clients are able to pay for the service)
- acceptability (whether the service is acceptable to clients).

We based our initial thinking about the barriers to health care that carers are likely to confront on this earlier body of work. However, as the data extraction and analysis progressed, it became apparent that existing frameworks were not ideally suited to our purposes. This was because the evidence from the research and evaluation reports included in the review identified that carers faced additional access problems that models for patient groups as a whole could not easily accommodate. Consequently, we developed our own typology to describe the barriers to access to health care for carers, a typology that drew on both existing models and our analysis of the literature.

The new typology, shown in Box 3.1 below, includes barriers faced by all patient groups, together with the additional ones we identified that were

specific to carers. Those that are similar in nature are grouped together into one of five different types of barriers to access; some examples of discrete barriers are included to help illustrate the 'barrier-within-a-barrier' coverage of each 'umbrella' heading. The strength of the typology lies in the fact that it distinguishes between different phenomena that hinder equitable access. This disaggregation is one that is valuable to policymakers and practitioners because they can then apply more appropriately targeted strategies to overcome barriers. The typology of barriers provides the framework and organising principle for our examination of access to health care for carers. In this and the following chapter, we take each of the five different barriers in turn and report the evidence relating to each.

Box 3.1 Typology of barriers to access to health care for carers

Professional characteristics

professionals' personal characteristics; professional awareness of carers; professionals' approach and attitudes towards carers.

Service issues

appointment systems; waiting lists, admission criteria; follow-up; staffing; agency policies and practices; eligibility criteria; identification systems for recording patients who are carers; costs/charges; proximity; transport; physical environment of service premises; parking facilities.

Language or cultural issues: language differences

cultural beliefs and preferences; appropriateness of services in terms of cultural, religious and language needs; racial prejudice and discrimination.

Carer or care recipient characteristic

help-seeking behaviour; individual preferences; perceptions of quality of care; perceptions of need; financial resources; anxiety; previous experience; community and family support; perceived availability of services; willingness and interest in obtaining services.

Information and knowledge issues

information about, and knowledge of, available services and procedures; medical confidentiality issues.

3.3 Nature and organisation of evidence

The first point to make is that we found a paucity of research directly focusing on carers' access to health care. In total, just 32 studies are reviewed. These 32 studies varied in terms of how they addressed our central research question, study design and strength of evidence. Twenty of these studies identify barriers to health care; the remaining 12 identify barriers to respite care and short breaks. We have used respite services and short breaks as an exemplar of a service that is regarded as one of the key formal support interventions to alleviate the stress of caring (Rudin, 1994; Strang and Haughey, 1998), and which carers have identified as critical to their caring

efforts (Cotrell and Engell, 1998), but perversely is known to have low utilisation rates (Cohen-Mansfield *et al.*, 1994; Toseland *et al.*, 2002). Furthermore, and as emphasised by contributors to the consultation, without respite care of one form or another, some carers may find it difficult to visit their family doctor or hospital to attend to their own health care needs.

The majority of the 32 studies were cross-sectional. Some 13 used qualitative methods. These generally comprised in-depth interviews; across the total 13 studies, interviewees included carers, GPs, hospital consultants, nurses and social services professionals. Ten studies used quantitative methods implementing, for example, postal surveys or structured interviews; none of the ten studies was experimental involving an intervention of any sort. The remaining nine studies used mixed methods. A small number of researchers employing mixed methods collected both quantitative and qualitative data using, say, standard outcome measures together with in-depth interviews; however, the majority collected qualitative data from, for example, interviews, focus groups and participant observation.

From the methodological perspective, we felt that it was important to be discriminatory in terms of strength and type of evidence, rather than integrating sets of findings, irrespective of whether they were based on strong or weak evidence, and were derived from the literature review or the consultation. Consequently, and in line with other recent literature reviews (Towner *et al.*, 2002), the chapter reports the evidence for each specific barrier under five different categories, ordered as follows:

- core studies
- intermediate studies
- supplementary studies
- respite studies
- consultation.

We explain what we mean by the terms 'core', 'intermediate' and 'supplementary' in the paragraphs below. While this approach does result in overlaps as similar evidence is presented in different categories, at the same time it is useful in that it gives a sense of the strength, or weakness, of the evidence base.

3.3.1 Core studies

Seven studies out of the total of 32 are particularly strong; they represent the best evidence available and we call these our 'core' studies (see Table 3.1). They are good-quality pieces of research and contain data that have a direct bearing on issues relating to access to health care for carers. Appendix 7 contains fuller details: study identification numbers (these numbers are referenced in the main text of this report as superscripts as, for example, [1; 2; 3]); author(s); study aims; carer group; method of data collection; sample; type of barrier(s) identified according to the barrier typology; setting.

Table 3.1 Core studies (n=7)

ID number	Author(s)	Main aims of study	Research design and study typology design code
1	Simon and Kendrick (2001)	To determine current practice and views of general practitioners and district nurses on their role relating to carers	Quantitative methods B3
2	Henwood (1998)	To examine carers' health and their experiences of the NHS	Quantitative methods B3
3	Sisk (2000)	To investigate whether the perception of burden is related to the health-promoting behaviours of carers of the elderly	Quantitative methods B3
4	Leeds Family Health (1996)	Report of a study of carers and primary health care in Leeds	Mixed methods B3
5	Burton *et al.* (1997)	To seek knowledge about preventive health practices of carers	Quantitative methods B3
6	Ward-Griffin and McKeever (2000)	To examine the relationship between community nurses and carers looking after older persons in urban Canada	Qualitative methods B3
7	Twigg and Atkin (1994)	To examine how service providers respond to carers	Qualitative B3

3.3.2 Intermediate studies

Our second group of studies, shown in Table 3.2, also contains seven studies. We have called this batch the 'intermediate' studies in order to indicate that they focus on the central issue of access to health care to a lesser extent and/or their quality is somewhat less robust. Nonetheless, we are including them in the review because they are useful in filling some of the gaps in terms of, say, specific carer groups or generic health care services. Fuller details can be found in Appendix 8.

Table 3.2 Intermediate studies (n=7)

ID number	Author(s)	Main aims of study	Research design and study typology design code
8	McIntosh *et al.* (1999)	To assess whether dementia care is stress-provoking, and examine doctors' and nurses' perceived roles with people with dementia and their carers	Quantitative methods C1
9	Arksey *et al.* (2000)	To examine the impact of the Carers (Services and Recognition) Act 1995 in four local authority social services departments in northern England	Mixed methods B3
10	McClure (2001)	To ascertain school nurses' knowledge and awareness of school-age caregivers	Qualitative methods C1
11	Chang *et al.* (2001)	To explore older carers' mammography participation and the facilitators and barriers to screening	Quantitiative methods C1
12	Aldridge and Becker (1993)	To look at the lifestyles and experiences of young carers in Nottingham	Mixed methods B3
13	Frank (1995)	To investigate the needs of young carers	Qualitative methods C1
14	Bibby and Becker (2000)	To document the experiences of young carers	Qualitative methods C1

3.3.3 Supplementary studies

The third group of studies contains what we have termed the 'supplementary' studies. Table 3.3 gives brief details; see Appendix 9 for further information. These studies are of sound quality, but generally speaking the authors do not disaggregate the findings in terms of one or more of the following: carers' or care recipients' views; access to health care for carers or care recipients; health care services or social care services. Nonetheless, the studies contain evidence that is helpful for this review as it indicates the similarities in barriers faced by both carers and care recipients attempting to gain access to both health and social care.

Table 3.3 Supplementary studies (n=6)

ID number	Author(s)	Main aims of study	Research design and study design typology code
15	Walters *et al.* (2001)	To explore patients' and carers' help-seeking behaviour and perceived barriers to meeting unmet needs	Mixed methods B3
16	Ward and Cavanagh (1997)	To idenitfy carers' health and social care needs	Qualitative methods B3
17	Katbamna *et al.* (1998)	To establish the nature of caring responsibilities undertaken and the impact caring has on British South Asian carers	Mixed methods B3
18	Beaver *et al.* (2000)	To provide insights into perspectives of users, their lay carers and bereaved carers on palliative care service provision	Qualitative methods B3
19	Gerrish (2001)	To examine the nature and effects of communication difficulties between district nurses and South Asian patients	Mixed methods B3
20	Neufield *et al.* (2002)	To understand how immigrant women carers accessed support from community resources and identify the barriers to that support	Mixed methods B3

3.3.4 Respite studies

The last group comprises the 12 studies examining respite services and short breaks (see Table 3.4 and Appendix 10). Given they all take respite care as their focus of study, we felt it was appropriate to report these together. All the 'Respite' studies present trustworthy findings; they report on the barriers carers face in relation to accessing respite care and short breaks, and from this point of view can inform the analysis.

Table 3.4 Respite studies (n=12)

ID number	Author(s)	Main aims of study	Research design and study design typology code
21	Frost (1990)	To examine the provision of respite care and carers' evaluations of this support	Mixed methods B3
22	Hatton *et al.* (1998)	To examine the support needs of South Asian families with a person with learning difficulties	Quantitative methods B3
23	Bruce and Paterson (2000)	To understand how carers of dementia sufferers gain access to community support and to determine potential barriers for carers	Qualitative methods B3
24	Bruce *et al.* (2002)	To investigate GPs' referral to community support services for dementia sufferers and their carers	Qualitative methods B3
25	Netto (1998)	To investigate the need for, use of and preferences for respite services among ethnic minority carers of older people	Qualitative methods B3
26	Baxter and Baxter (2000)	To study users' and carers' experience of services	Quantitative methods B3
27	Clarke and Watson (1991)	To investigate caring for a dementing person in the community	Qualitative methods B3
28	Cohen-Mansfield *et al.* (1994)	To examine reasons for nonutilisation of adult day care	Quantitative methods B3
29	Hayes *et al.* (1996)	To describe the characteristics of respite services across England	Mixed methods B3
30	Clarke and Finucane (1995)	To undertake a needs assessment for respite for elderly people in receipt of care	Quantitative methods B3
31	Morgan *et al.* (2002)	To examine dementia care	Qualitative methods B3
32	Godfrey and Townsend (2001)	To explore barriers to take up of respite services for South Asian carers of people with dementia	Qualitative methods B3

In what follows, we present the evidence about each barrier from the literature review and the consultation. We give an indication of whether the key points emerge from stronger or weaker studies to avoid over-interpretation and misleading results. Each sub-section ends with a short discussion of ways forward. The ideas we present for remedial action are ones that seem to us to be worth exploring in order to test their potential for overcoming barriers to accessing health care. We make more conclusive recommendations for strategies to improve access in the final chapter (Section 5.4).

3.4 Barriers related to professional characteristics

Some 17 of the 32 studies included in this part of the review identified professional barriers to accessing health care. Key ways in which professional behaviour induced or created barriers that were identified were: lack of recognition of the caring role and awareness of the needs and issues involved; professional uncertainty about roles and boundaries; reactive rather than proactive approaches; prioritising the care recipient at the expense of the carer; professional models, conceptualisations or stereotypes of carers that may not be conducive to meeting their needs. The evidence base is relatively strong, for example five of the seven core studies report relevant evidence, much of which is in turn confirmed in the other categories as well as the consultation.

3.4.1 Evidence from core studies[1;2;4;6;7]

Simon and Kendrick (2001) undertook a postal survey of GPs and district nurses, focusing on their role relating to carers.[1] One of the issues to emerge related to role definition. Some GPs commented about 'role fatigue', and many respondents from both study groups regarded supporting carers as the task of someone other than themselves (often, each other). The majority of both groups saw their role in supporting carers as reactive, in other words they should only become involved when asked – generally, only when a problem had already arisen. As the authors note, this indicates a major gap between the proactive role envisaged for primary care services by the government and carers' organisations, and the role that GPs and district nurses see for themselves.

A study by Leeds Family Health (1996) of carers and primary health care did indeed find that GPs adopted a reactive role.[4] The project involved a consultation with carers, professionals whose work brought them into contact with carers, and GP practice staff. When asked whether the GP enquired about the effect of caring on their own health, the majority of carers reported that the doctor did not ask.

Similar findings are confirmed elsewhere. A large-scale postal survey conducted by Carers UK (Henwood, 1998) showed that respondents experienced difficulties in being seen as patients in their own right, summed up in the title of the report *Ignored and Invisible?*[2]

Based on evidence from a large-scale qualitative study, Twigg and Atkin (1994) developed four models or conceptualisations of responses of health and social care professionals to carers: carers as resources, carers as co-workers, carers as co-clients, and superseded carers.[7] They found that GPs did not recognise that carers might benefit from support, instead seeing carers in terms of their relationship to the care recipient. In so far as GPs did perceive carers as such, it was often with an instrumental emphasis, regarding them as a form of resource. Because GPs were used to understanding problems within a medical definition, they found it difficult to respond to carers who consulted about problems that were diffuse and who wanted to talk generally about their situation. The researchers argued that doctors' professional values did not encourage them to see women as carers in the same way as they saw men as carers (women were seen to be performing caring work as part of their general domestic role). Community nurses had a role in counselling carers and in giving information, although limited resources meant this activity was under threat. Twigg and Atkin identified different ways in which carers were incorporated into nurses' practices: by amplification, by standing one step back, by taking over, by giving the carer a boost, and by compensation. Carers were likely to receive more or less support, in relation to either their own or the care recipient's needs, according to how they were incorporated into the practice of the community nurse.

Finally, a study from Canada presents an alternative model or conceptualisation of relationships between community nurses and carers which can influence who gets help and why.[6] Ward-Griffin and McKeever (2000) draw on data from qualitative interviews with carer–nurse dyads to categorise four distinct types: nurse–helper; worker–worker; manager–worker; and nurse–patient. While concern for the well-being of the carer was generally minimal, in the nurse–patient relationship carers were seen as people in need of care in their own right, especially those women who were elderly or who had chronic health conditions themselves, yet felt that they had no choice but to ignore their own health in order to look after their relative.

3.4.2 Evidence from intermediate studies [8;9;12;13;14]

Three of the intermediate studies focus on issues relating to young carers.[12; 13; 14] The findings about professional behaviour and beliefs, and how these phenomena create barriers to access to health for carers, are consistent with points made in the core studies. For instance, two studies report that children and young people may not be recognised by doctors as young carers, and/or their accounts of caring and how it was affecting them believed.[12; 13] Aldridge and Becker (1993), the authors of one article, note the traditional bias in medicine whereby doctors tend to define the problem first in medical terms and secondly in terms of the individual patient, an approach which can lead to carers being overlooked.[12] This was even more likely in the case of those young carers in the study who were either not assertive enough in their dealings with GPs, or were unwilling or lacked confidence to approach their doctor regarding their own needs (see barriers related to carer or care recipient characteristics). In a different study that had collected data from

young carers and a range of health care professionals, Frank (1995) found a reluctance, particularly among GPs, to acknowledge that young carers' needs crossed all boundaries and therefore were the concern of all agencies and not just Social Services.[13] The third study included written accounts of life as a young carer, which showed that professionals sometimes failed to understand the work that young carers performed.[14]

A survey of GPs and nurses attending a series of dementia education seminars asked about professional roles, attitudes and stressors in relation to the management of people with dementia.[8] Over half found dealing with people with dementia and their carers stressful. GPs reported more negative attitudes to dementia care than did nurses. Around one-third of both GPs and nurses felt they had 'nothing' or only 'a little' to offer in support of carers for people with dementia. These sorts of negative attitudes on the parts of primary health care professionals are potential barriers to carers accessing health care support.

The remaining intermediate study looked at carers' experiences of health care as one part of a larger study.[9] Arksey *et al*. (2000) found that some carers felt they had difficulty in getting their own health needs recognised by doctors. A handful of older carers felt that their GPs were biased towards patients from a younger age group, and did not understand older people and/or the particular problems they faced as carers, an issue raised by contributors to the consultation.

3.4.3 Evidence from supplementary studies [15;16;17]

Three of the supplementary studies contained evidence of professional barriers to accessing health care. Consistent with the point about ageist attitudes above, a recurrent theme in Walters and colleagues' (2001) study of older people and their carers was that participants felt that help had been denied due to age attribution.[15]

In Katbamna and colleagues' (1998) study of carers from four South Asian communities, the researchers examined carers' experiences of primary health care teams.[17] Consultations were reported to be rushed and inadequate, with doctors giving little or no explanation; often, carers' questions or anxieties were left unaddressed or not taken seriously. GPs were perceived to be patient-focused; female carers in particular spoke about a lack of recognition of their caring role, their own health needs not being taken seriously, and not being asked how they were. Carers reported being spoken to impatiently, with sarcasm or even rudely, both by GPs and other members of the primary health care team (often receptionists).

Another study involving a series of focus groups of adult carers of dependants with a range of long-term problems reported similar findings in relation to: feeling that professionals did not focus on the carers themselves; and insensitive, condescending and disrespectful responses by professionals.[16]

3.4.4 Evidence from respite studies [23;24;31;32]

Bruce and Paterson's (2000) study of Australian carers of dementia sufferers found that carers believed GPs failed to refer them to the Aged Care Assessment Team, who would then be able to assess individuals for respite care and community support programmes.[23] Reasons included: a lack of diagnosis of dementia; failure to realise the extent of carers' problems or the level of burden of care they experienced; and that doctors did not know what support was available. Diagnosis was also discussed in another Australian study, where it was suggested that doctors saw shortage of time as problematic because it led to inadequate assessment and diagnostic difficulties.[24] Carers' input into the diagnostic process was commented on in a study by Morgan *et al.* (2002).[31] These researchers found that professional failure to recognise and validate carers' observations of cognitive decline in their relatives in turn led to problems in reaching a diagnosis of dementia. Early diagnosis could alleviate the stress carers felt arising from uncertainty and would permit carers to access key support services sooner.

Professionals' attitudes were found to act as barriers to respite care. One study found that carers were deterred from accessing services after receiving unhelpful responses from practitioners at the referral agency.[23] Professional attitudes were also highlighted in Godfrey and Townsend's (2001) study of Asian carers where interviews with health and social services staff suggested that professionals worked with explicit and inappropriate views of the type of services that would be appropriate to offer to Asian families.[32] Staff might ration scarce resources and were less likely to explore the need for respite care if carers were perceived to have other relatives available to help. Health and social services staff seemed to operate on the basis of implicit or tacit ground rules about what was appropriate to discuss with families, what could be provided, and who was most in need. If workers thought that a family was coping, respite care was less likely to be discussed.

Lack of understanding about the impact of dementia on the care recipient was an additional factor identified in affecting service use, for example not understanding that carers may lose social contact so not appreciating the value of using respite to enable the carer to take part in social activities.[31]

3.4.5 Evidence from consultation

Contributors were in agreement that professional lack of awareness of carers' issues was one of the key barriers that carers faced when accessing health care. Ignorance about carers and their needs in general was felt to be high, and ignorance about how to support young carers in particular even higher. Even if health staff did identify a carer, it was felt that they were often uncomfortable about exploring the pressures of caring.

Contributors felt that professionals tended to focus on the care recipient at the expense of the carer, and therefore were less likely to identify the potential impact of the situation on the carer's health. A potential consequence of this sort of approach was that carers might then find it more difficult to raise issues connected with caring themselves. Failure to see carers

in a holistic way (i.e. in the context of their other responsibilities and own health needs) could have a negative impact on the carer's health (and render advice given about the care of the person supported inappropriate).

The 'reactive' culture of health services was said to work against a preventive approach that could protect the health of carers and prevent crises such as emergency admissions to hospital.

Some contributors expressed the view that professionals often failed to treat carers as partners or colleagues in health care. They did not routinely consider carers' needs for preventive measures to protect their health, such as moving and handling training, vaccination, or information. If health professionals were reluctant to refer outside the health sector for whatever reason, this might inhibit carers from accessing effective support services from voluntary and social care agencies.

3.4.6 Summary and ways forward

We found a strong consensus between the literature review findings and the consultation about professionally created or induced barriers to health care. To repeat, key barriers identified were: lack of recognition of the caring role and awareness of the needs and issues involved; professional uncertainty about roles and boundaries; reactive rather than proactive approaches; prioritising the care recipient at the expense of the carer; professional models, conceptualisations or stereotypes of carers that may not be conducive to meeting their needs. As noted earlier, the evidence base is comparatively strong.

These are difficult issues to address, especially on a short-term basis. Having said that, awareness training from carer support workers (see examples of primary care initiatives discussed in Chapter 4) about carers' needs and carer-sensitive practices for all health professionals and front-line staff has the potential to introduce changes in attitudes and behaviours. Longer-term solutions lie in changing the overall culture. Practically speaking, this means including education about maintaining carers' physical and emotional health, and working more preventively, as an integral part of routine patient care in the medical and nursing curriculum.

3.5 Barriers related to service issues

In all, 14 studies identified barriers arising from service issues. Key features identified that served to obstruct carers' access to health care included: GP surgeries not identifying carers and/or 'tagging' carers' records; lack of training in carers' issues; 'gate-keeping'; inflexible appointment systems; waiting times; transport and car parking; costs. The evidence base is again comparatively strong, and the same or similar barriers were documented in all four categories of literature, as well as in the consultation.

3.5.1 Evidence from core studies [1;2;4]

Not being identified as a carer is a key barrier to accessing health care, yet the findings from Simon and Kendrick's (2001) survey of GPs and district nurses showed that GPs in particular found identification difficult.[1] This reflects the fact that many carers do not see themselves as such and, even if questioned on this issue, might not declare themselves as carers. Identification can be even more difficult if the care recipient is registered with a different doctor or practice, or is not on the caseload of a district nurse.

The review found evidence of wide variation in the recording of carer status, in spite of this being a government priority (Department of Health, 1998). Simon and Kendrick (2001), for example, found that fewer than one in four GPs, and only one-third of district nurses, routinely recorded whether someone was a carer.[1] Similarly, while research in Leeds showed that general practice staff thought it was important to identify patients who were carers, actual practice was similarly varied.[4] The majority of GP practice staff respondents said that they did not identify or tag carers' records. Those who did would add a note on the patient's record or on the computer record (usually the carer's record but sometimes the record of the person being cared for). Several marked the over-75 check card if the patient was a carer, a procedure that would identify only elderly carers.

Simon and Kendrick's (2001) survey also showed that, as far as training was concerned, the majority of GPs and district nurses had not received any training about the health of carers.[1] Training varied from reading a magazine article to training on modular courses. The analysis showed that receipt of training was positively associated with the recording of carers and routine follow-up.

Carers taking part in the Leeds research were asked their views about the service offered by GP practices.[4] Generally, carers found the service convenient except for arrangements for appointments which nearly one-quarter of carers reported was inconvenient. One or two practices had instituted special arrangements that could be made for appointments to fit in with carers' needs.

Carers taking part in the Carers UK survey expressed concerns about their own needs for hospital care, especially those who already had their own health problems.[2] Respondents with their own health problems identified the

uncertainties when on a waiting list for hospital admission, and the difficulties in trying to plan ahead to make any necessary care arrangements (for example, organising respite care) to cover their absence. Outpatient appointments could be at some distance away, especially for carers in rural villages. However, only a small minority used public transport to reach outpatient appointments; the majority went by private car and the remainder either had transport arranged by the hospital or used a taxi.

3.5.2 Evidence from intermediate studies [11]

A study conducted by Chang *et al*. (2001) in the USA looked at mammography screening behaviour in older women carers.[11] Women in higher socioeconomic groups with insurance had higher screening rates. Cost was one of the reasons that carers gave for not having mammograms.[a]

3.5.3 Evidence from supplementary studies [15; 16; 17; 18; 20]

Barriers relating to making arrangements and planning were identified in some of the supplementary studies. For instance, in the study by Beaver *et al.* (2000) of primary care services received during terminal illness, carers commented that they often had difficulties in planning, especially when they did not know in advance whether or not they were going to receive assistance (a sitting service, for instance, where little advance notice might be given that the service would be available).[18] Another study referred to the opposite situation where services such as respite care had to be booked months in advance, which in turn compromised any opportunity for spontaneity in carers' lives.[16] Carers in yet another study reported having to go on waiting lists for a service, when their perceived need was immediate.[20] For some carers, the time for which the service was available was insufficient.

South Asian carers taking part in the study by Katbamna *et al*. (1998) reported difficulties in relation to getting in touch with their GP; often, these criticisms were directed at reception staff who were thought to 'block' access.[17] They complained that they had to wait too long to speak to the doctor over the telephone or that they were unable to speak to the doctor at all. Inadequacies in the appointment system meant that carers' needs were not considered and they experienced lengthy waits before they could see their GP – sometimes of up to a week or more. Both male and female carers suggested the need for more flexible appointment systems, that they should be prioritised and, wherever possible, seen on the same day, and that they were given longer consultations. Carers complained that physical access problems sometimes impeded their ability to see the GP, for instance the surgery had too many stairs.

[a] It is known that lack of money is a major problem for carers (Parker, 1993). However, the cost issue is only likely to affect women carers in the UK who fall into particular age bands because free breast screening is routinely offered every three years to all women in the UK aged between 50 and 64. Work is being carried out to extend the programme to women up to and including the age of 70 by 2004.

A study of older people and carers identified a range of barriers to seeking help from health and social care services.[15] These included: perceived service failure, for instance a failure of the provision of a service or inadequacies in the service provided; rationing of services; eligibility for services; cost issues.

Carers taking part in a study of primary care services received during terminal illness reported that it could be difficult to get a rapid response from health care professionals when they wanted to talk about problems they had to deal with that arose from their caring activities.[18] Participants also commented that the casual approach of occasionally 'popping in' adopted by some health care professionals could create difficulties if visits did not co-ordinate with their own schedules. Without set appointment times, carers could miss the opportunity to talk to the doctor or nurse themselves to seek information.

Lastly, immigration is a topical issue in this country, yet we found no UK studies that focused specifically on immigrant carers. However, we did identify a Canadian study[20] that explored how immigrant women caregivers accessed health and social care support.[b] The authors of the study found that barriers to accessing support included structural ones arising from immigration policies. The study also found transport to health care services could be a problem. For example, car parking could be hard to locate and/or some distance away from the surgery; it could also be expensive. Public transport was one alternative, but this was especially difficult for those individuals who did not speak English.

3.5.4 Evidence from respite studies [21;24;28;29;30;31]

From the outset, organisational barriers to respite care can arise. A study of black and ethnic minority carers concluded that groups that were traditionally disadvantaged in terms of service receipt were also disadvantaged in relation to accessing respite.[29] In practice, this meant that carers from black and ethnic minority communities, or carers of people with mental health problems, were not widely targeted.

A study of eight innovative respite services in the UK indicated that time-lags between initial service requests and eventual receipt of services were caused by having to pass through assessment or referral procedures.[29] Immediate access was rarely available; waits for home-based services could take up to one year, although just over eight weeks was the average. A paucity of available places for short-stay and day care was identified by a study of carers in East Sussex.[21] In the same study, the inflexibility of short-stay care to respond to emergencies was also problematic; some places had to be booked a year in advance of being needed.

When services are accessed, barriers continue to occur. In a study following up over 100 carers who had inquired but not proceeded to enrol in day-care centres, Cohen-Mansfield *et al.* (1994) found that the services provided did

[b] Like the UK, Canada has a universal health care system; in practice, however, coverage available to immigrant families can vary with immigration status and province of residence. While immigration practices are likely to be different in the two countries, it is not impossible that UK policies will have a similarly negative impact on immigrant carers' access to health care.

not meet carers' exact requirements in a number of ways.[28] For example, service hours were inconvenient; the level of impairment among the centre's participants was felt to be incompatible with that of care recipient; and there was a lack of a particular service or treatment. Concern about the quality of care was mentioned in another study.[21] Carers expressed concern about staff training, skill, experience and levels of care and attention. They also complained of a lack of stimulus and organised activities. In some cases the quality of care provided led to a carer choosing not to take up short-stay or day care, and in other cases to conflict as to whether to use a service.

Transport emerged as a theme in several studies in terms of availability,[28] logistics[28; 30; 31] and cost.[28] The study of non-enrolment in adult day-care centres found that transportation problems was a reason why some carers decided not to use the service.[28] These barriers may be exacerbated in rural areas. A study of rural carers in Canada reported logistical problems in terms of difficulties moving care recipients in and out of cars and the distance to reach services.[31]

Cost to carers emerged as a barrier to accessing services in two studies.[28; 31] In one American study, nearly 10 per cent of respondents reported cost as a prohibitive factor in accessing adult day-care services.[28] Even where home care services were subsidised, cost was still found to be a deterrent to access. This was identified as an inability to afford the services and believed to be related to frugality.[31]

Bruce *et al.* (2002), in their study of Australian GPs, found that there was a lack of financial remuneration for doctors for the time required to support families who cared for people with dementia.[24] As noted in the previous section on professional barriers, lack of time was felt to be a problem that could result in inadequate assessment and diagnostic difficulties.

3.5.5 Evidence from consultation

Contributors suggested that carers could be deterred from help seeking by the rigidity of appointments and long waiting times, which might not fit well with their other commitments and responsibilities – especially for those carers who combined caring with paid work.

Those carers unable to leave the care recipient for any length of time, and/or rural carers, could be deterred from travelling long distances for an appointment with a GP or hospital consultant if they had problems organising substitute care. Young carers also faced logistical problems, because a parent who was sick or disabled was unlikely to be able to drive them to the surgery or hospital. Some contributors suggested that GPs and other health care professionals often failed to recognise these barriers and seldom offered home visits proactively. Likewise, offers to arrange transport (e.g. through Dial-a-Ride schemes) for sitting services were seldom forthcoming. Carers, for their part, were often unaware that they could request these services.

It was felt that many services did not take active steps to identify and record those patients who also had caring responsibilities, particularly if the carer was not co-resident, or registered with a different practice.

The cost of certain health services was felt to be a deterrent to some carers. In many areas, some types of health care (e.g. flu vaccinations) had to be paid for by carers, even though they were offered free to other vulnerable patient groups, health staff and paid carers. It was felt that complementary therapies could also benefit many carers, but again the cost might well be a deterrent (see Chapter 4). It was also suggested that because many carers were on benefits, and because the option of direct payments was not widely publicised and/or taken up, carers might feel unable to afford alternative arrangements.

3.5.6 Summary and ways forward

Examples of similar barriers relating to service issues emerged from both the literature review and the consultation. The evidence base is again relatively strong. To repeat, the key barriers that were identified were: GP surgeries not identifying carers and/or 'tagging' carers' records; lack of training in carers' issues; 'gate-keeping'; inflexible appointment systems; waiting times; transport and car parking; costs.

Potential solutions spring to mind, with different levels of ease and cost of implementation; generally speaking their effectiveness remains untested. The 'easier' ones include: identifying and tagging carers' medical records systematically; including a carer question on the regular over-75s health check; hospital admission and discharge notes to include questions to identify carers; flexibility in appointment systems, and offering home visits; giving carers priority on waiting lists; offering pre-booked outpatient appointments and hospital appointments; appointing a 'carers lead' in GP surgeries. Some of these suggestions are in the process of being addressed through the new Advanced Access initiative now being implemented in primary care, and the National Booking Programme – developments which have the potential to improve access for all patient groups and not just carers. Issues relating to transportation and financial remuneration are more difficult to address, although in theory the new GMS contract that comes into force in April 2004 could be a useful vehicle here.

3.6 Barriers related to language or cultural issues

Eight studies identified barriers related to language or cultural issues that served to inhibit carers' access to health care. The key problems identified included: carers not being able to speak English; inadequacies in translation and interpreting services; racial prejudice and stereotyping; professionals' lack of knowledge about cultural and religious practices. The evidence base is, however, relatively weak. For example, no studies in the core group, or the supplementary group, reported evidence about barriers arising from language or cultural issues. In the event, the most reliable evidence was contained in those studies focusing on respite care and short breaks. The views of contributors to the consultation confirmed the points raised in the empirical studies.

3.6.1 Evidence from supplementary studies [17;19;20]

Not speaking English can be a barrier to accessing health care. Neufield and colleagues' (2002) study of immigrant women carers in Canada found that the women were hampered in their ability to access services by inadequate skill in English, even when they had attempted to learn the language.[20] Inability to speak English was a barrier to expressing their feelings and talking about emotional needs, and also limited the choice of potential professionals. Those carers who valued privacy were reluctant to disclose personal problems and feelings to a stranger. Some women deliberately chose to isolate themselves, and lacked connections to others who might facilitate contact with community services. Others lacked the confidence to make their needs known, or feared disclosure to relatives who might consider them incompetent. Conflict between beliefs in traditional herbal medicine and Western medicine was problematic for some Chinese carers; others lacked knowledge about Western medicine. Previous experiences in their country of origin affected carers' perspectives on community support.

Gerrish (2001) also found that many of the carers in her study of interactions between district nurses and South Asian patients and their carers were unable to speak English, and were reliant on either the care recipient or other family members to interpret.[19] While the district nurses offered to refer carers to other support services, they were often unable to discuss in detail how the carer was coping with the physical and emotional burden of caring. In contrast, nurses were able to offer more psychological support to those South Asian women carers who spoke English. Organisational issues relating to interpreting services available via the local NHS trust meant that district nurses rarely utilised them. Nurses regarded the service as inadequate because of under-resourcing and difficulties with access. Interpreters had to be booked in advance, usually with two day's notice. This requirement was not conducive to the nature of the nurses' work, which often needed a more immediate response. Some district nurses lacked confidence in the detail and accuracy of

the translations provided by the interpreters, and few nurses had received training in working with professional interpreters.

South Asian carers taking part in the study by Katbamna *et al*. (1998) also commented that those translating services that did exist should be used more frequently by health care professionals.[17] Carers from all four South Asian communities referred to the issue of racism. They felt that Asian people were stereotyped by professionals, for instance, as not being able to speak English whether that was the case or not. There was a feeling that services were not provided or were refused because of the issue of ethnicity. Bangladeshi Muslim female carers felt that just being Bangladeshi meant that they were not given any respect or valued as people by professionals, regardless of whether this was in a surgery or hospital setting. Some groups would have valued access to a same-sex doctor; this was seen to be particularly important for women. It was felt that professionals' lacked sufficient knowledge about the cultural and religious aspects of carers' lives.

3.6 2 Evidence from respite studies [22;25;26;28;32]

Four studies noted language barriers to respite care.[22, 25, 28, 32] Baxter and Baxter (2000) found that among black and ethnic minority carers, language and communication were principal barriers to service access, as these led to carers being less informed and lacking the skills to provide support.[26] Netto (1998) found that the isolation of ethnic minority women carers from information and services was exacerbated by the inability of many to speak English.[25] In spite of these language barriers, other studies have found that there was little provision for people who did not speak English,[32] and a paucity of staff who could speak the same language as the carer.[22]

Professionals attached importance to the communication and language skills of formal carers within respite services.[32] Investigating the need, use and preferences of ethnic minority carers for respite services, it was found that with regard to sitter services it was important for the sitter be able to speak the same language as the care recipient. In respect of residential respite care, there was also concern about care recipients (not) being able to communicate with others.[25]

Cultural barriers to respite care were also reported.[22, 25, 26, 32] Baxter and Baxter (2000) found that ethnically insensitive services combined with discriminatory practices acted as a deterrent to the uptake of respite services.[26] These authors indicated the reluctance of black and ethnic minority carers and users to take up services believed to be either culturally inappropriate or that did not afford them dignity and/or respect. As mentioned in relation to professional barriers above, professionals worked with explicit views of what services would be appropriate to offer Asian families; often families were not integrated into specialist dementia services.[32] In a study of South Asian carers of people with learning difficulties, over one-fifth cited racial discrimination within services as a barrier to service uptake.[22]

Two studies reported the wish for same-sex staff to look after care recipients.[32, 25] Health and social services staff suggested that the issue of

appropriate gender of care workers was of equal significance to language as far as the development of culturally appropriate services was concerned.[32] In their view, many older people wanted same-sex staff. This choice was confirmed in a second study that reported carers' preference for sitter services that used staff of the same sex as the people they were looking after.[25]

Other themes emerging as barriers to accessing respite care were: culturally inappropriate diets[22, 25]; culturally inappropriate activities and staff provision[22]; and problems meeting religious needs (also related to dietary requirements).[25, 32] One study found that some carers explained their reluctance to take up residential respite care in terms of feeling that they would in any case have to stay with the care recipient, even if the respite stay was for up to two weeks.[25]

3.6.3 Evidence from consultation

Contributors confirmed the literature review findings, expressing the view that language was one of the main barriers to health care, especially for those individuals who were newcomers to the UK. If the main carer did not speak any English, they might not attend appointments with the carer recipient; as a result, their own health needs would remain invisible to health staff. Even if the carer did attend appointments, they might use younger/other family members to interpret and feel inhibited in speaking openly about their own health concerns.

While it was acknowledged that interpreting services could help to overcome such barriers, it was pointed out that they were rarely used by nurses – either because they did not consider it a priority, or because they lacked training and did not therefore feel comfortable with using the service. Even when interpreters were used, it was felt that they were not always adequately trained and briefed to understand the issues, some of which could be extremely sensitive (for example, explaining that an illness was terminal). An additional barrier was that the care recipient and/or carer might be wary of trusting the interpreter because they might well come from the same small community. On the other hand, if no interpreter had been arranged, the professional might then expect the carer to explain points relating to diagnosis and treatment to the care recipient in their own language. If the carer felt anxious about this responsibility, they might instead keep silent, which could in turn exacerbate their own stress.

Some black and ethnic minority community groups were thought by contributors to be afraid of 'the system' – or of becoming known to the authorities – to the extent that they would not request health care even if they had a serious illness. Although these contributors acknowledged that all black and ethnic minority carers had to deal with some level of structural racism inherent in the health care system, this was felt to be particularly applicable to the mental health system, where contributors felt there was strong evidence of overt racism and of much higher rates of compulsory admission for black and ethnic minority patients. The problem was felt to be even more acute for refugees and asylum seekers, with one contributor stating that one in four were said to have mental health problems. With so little known

about their health needs and so little engagement with statutory services, it was felt likely that their carers faced particular barriers in accessing health care.

In the experience of some contributors, carers from black and ethnic minority communities were unlikely to seek or accept help unless health services showed themselves to be particularly culturally sensitive. Some women might not be willing to let anyone examine them, or would need their husband's permission to consent to treatment. They could suppress their own health problems for this reason. It was noted that, in some ethnic minority communities, there was also a strong stigma around certain diseases, such as cancer or dementia. Keeping silent about such conditions put additional pressure on carers and prevented them from accessing support systems for themselves.

Contributors believed strongly that respite services and short breaks were often culturally inappropriate or unacceptable to black and ethnic minority communities. As a result, carers were reluctant to arrange substitute care in order to attend health appointments. Asian carers in particular often felt they needed to rely on the family, finding it hard to accept and access respite services for cultural reasons.

3.6.4 Summary and ways forward

To recap, the key problems identified in relation to language or cultural barriers included: carers not being able to speak English; inadequacies in translation and interpreting services; racial prejudice and stereotyping; professionals' lack of knowledge about cultural and religious practices. The evidence base is, however, relatively weak, and a caveat needs to be placed on what conclusions can reasonably be drawn.

In the short term, increased attention could be given to assisting carers from black and ethnic minority communities with reading, writing and form completion. On a long-term basis, however, solutions to language difficulties are best provided by expanding professional translation and interpreting services within community settings, and at the same time training health care professionals to use them more effectively and encouraging a greater uptake in utilisation levels. In turn, better-quality service delivery has the potential to further carers' (and care recipients') trust in interpretation services. Improved professional education and awareness training about aspects of caring that are important for carers from black and ethnic minority communities may serve to address issues related to racial discrimination and lack of knowledge about cultural and religious practices. Given the high priority accorded user involvement in policy issues, thought could be given to including minority carers in planning policy and/or awareness training. A further long-term measure is the development of culturally sensitive services in relation to health care generally, and respite and short breaks in particular.

3.7 Barriers related to carer or care recipient characteristics

Fifteen studies identified barriers related to the characteristics of either carers or care recipients. Problems identified included: carers' approach to care giving and/or health promotion; carers' help-seeking behaviours; personal and/or cultural beliefs and preferences; care recipients' attitude. The evidence base is comparatively strong, in that 3 of the 7 core studies identified ways in which the behaviours and characteristics of carers could prevent them from accessing health care. So, too, did nearly three-quarters (8 out of 12) of the respite studies. The same or similar points were confirmed in the intermediate and supplementary studies, and also the consultation.

3.7.1 Evidence from core studies[3; 5; 7]

Twigg and Atkin's (1994) study examined the attitudes adopted by the carer to his or her caring role.[7] Each response was important in structuring how the carer negotiated and accepted health and social care services. They found that carers adopted three main responses: that of engulfment, of balancing/boundary setting and of symbiosis. Carers who were engulfed by their caring activities were less likely to ask for, or accept, help. This applied particularly where any help was aimed at them rather than the person they supported. In contrast, carers who adopted the balancing/boundary-setting mode were much more likely to access support. Carers in the symbiotic mode sought and accepted help, as long as it was not perceived to threaten their own role as carer.

Twigg and Atkin also found that the attitude of the care recipient was significant. At its most extreme, they were able to exclude carers from contact with professionals, especially in the hospital setting. In these sorts of cases, carers could remain invisible which in turn greatly reduced the likelihood of their role and own needs for support being recognised.

Two studies that examined health promotion activities gave insights into carers' practices in relation to preventive health activities such as visiting a doctor, taking part in screening examinations or obtaining recommended immunisations for influenza, pneumonia or tetanus.[3; 5] The researchers in one study found that being a high-level carer, defined as living with a spouse with activities of daily living impairments, had a negative effect on carers' ability to engage in positive preventive health behaviours.[5] There were significant associations between caring level and not finding time for doctor appointments and forgetting to take medications. Other health behaviours, i.e. missed doctor appointments, missed flu jabs and no time to replenish medications, occurred more frequently for high- rather than moderate-level carers but did not achieve statistical significance. Larger proportions of carers with a strong sense of control adopted good preventive health behaviours compared with carers with a weak sense of control.

The second study (Sisk, 2000) looked at health promotion and carer burden in carers of elderly people in efforts to increase understanding about the ability of carers to attend to their own health needs.[3] The findings indicated that those perceiving lower subjective burden practised more health-promoting behaviours. Sisk went on to suggest that feelings involved in caring, such as fear, pain, loss, and guilt, could interfere with carers' ability to keep in contact with medical help.

3.7.2 Evidence from intermediate studies [10;11;12]

Two studies focused on young carers. One small-scale study exploring the experiences of school nurses in respect of school-age carers found that many were already offering a confidential 'drop-in' service to which all school children were encouraged to bring their health concerns.[10] Young carers did use this service; while they wanted to talk to the nurses, they did not however want things to go any further. According to the nurses, the young carers did not want help, and they did not want their family to know that there were people who could help. As this was their wish, the nurses could do nothing to change the situation and instead would just listen to them.

The theme of anonymity recurred in another young carers study.[12] Aldridge and Becker (1993) found that some study participants worried about issues of confidentiality and wanted to obtain help 'anonymously' to ensure their privacy, possibly using a telephone help-line where it is not necessary to give a name and address (but see below). The authors also noted that young carers were not assertive in their encounters with family doctors. Not all were willing and confident enough to approach GPs about their own needs.

The third intermediate study looked at the facilitators and barriers to mammography screening.[11] Key barriers included carer procrastination, the fear of finding breast cancer, radiation exposure, fear of pain and feeling that mammographs were unnecessary. Carers with higher burden reported less frequent self- and provider-conducted breast examinations.

3.7.3 Evidence from supplementary studies [15]

A study by Walters *et al*. (2001) exploring older people and their carers' perceptions of barriers to meeting needs found that many participants felt 'resigned' to their situation and although they identified a problem did not intend to seek help for it.[15] Low expectations were a recurrent theme, often linked to resignation. Among carers, there was a sense of duty and endurance. Some had a sense of feeling overwhelmed with their responsibilities coupled with isolation, leading to difficulty in seeking help.

3.7.4 Evidence from respite studies [24;23;25;27;28;30;31;32]

Interaction between GPs and carers was identified as a barrier to accessing the appropriate services.[23, 24] For example, carers could feel unable to discuss their problems with GPs because of reticence, a lack of opportunity and a sense of shame.[23] An Australian study of carers of dementia patients found that carers believed that doctors were unaware of their problems and/or

support services, and were unskilled in dementia care. For their part, doctors reported that carers insisted they were coping even if the GP believed otherwise, and that carers were reluctant to consider outside assistance (see below).[24] Clarke and Watson (1991) speculated on whether carers accepted respite despite their own true needs and wishes, and/or those of the care recipient, if a social worker kept offering this service, because they felt obliged to take up the offer in order to safeguard future service provision.[27]

Several studies talked about stigma and labelling.[31, 32, 24] In one Canadian study of rural carers, the stigma of dementia was seen as being linked to mental health problems, and led to an unwillingness to admit to a dementia diagnosis.[31] This in turn could stop carers acknowledging the disease, talking about the difficulties they experienced, openly seeking out information about resources, and attending support groups.

In addition to the labelling of the care recipient, it was also the case that carers sometimes lacked recognition of their status as 'carers'.[25] Carers' belief that they should be able to manage without outside assistance, having pride in their own efforts, feeling guilty for accepting formal support and being concerned about using scarce resources before absolutely necessary were suggested as barriers to accessing respite care.[24] Carers commented they felt guilty and selfish if they used respite services, and that caring was their own responsibility.[27, 30, 31, 32] Carers also felt it was their duty to provide the care themselves.[28] Accepting a service was perceived as a public admission that a carer was unable to manage without help. As noted above, there was a desire not to be a burden on the system or to take help away from someone who needed it more. A legitimate reason to use respite was required: spending the time on oneself could be seen as 'frivolous'. Even if paying for respite, there was a desire not to be seen as accepting charity. There was an association of home care and respite with dependence and decline – 'the step before the nursing home'.[31]

Another barrier was the care recipient's attitude towards respite care. A study by Cohen-Mansfield *et al.* (1994) suggested that care recipients might not want to be in a group and/or denied they needed help.[28] Care recipients were resistant to the idea of community support.[24] There was an association with prior negative experiences.[28] The relationship between the carer and care recipient had a bearing on attitudes towards respite care. A study of ethnic minority carers found that care recipients were unwilling to accept residential respite care, and that both people wanted to be together, rather than split up.[25] A study of dementia carers suggested a variable response to carers accepting respite, related to the closeness of their relationship with the care recipient and not wanting to exclude them.[27]

3.7.5 Evidence from consultation

Contributors pointed out that one of the major barriers facing carers related to feeling unable to take time off from caring in order to attend a doctor's appointment, have an operation, or recuperate. Past experience of services perceived as inadequate could increase carers' reluctance to leave the care recipient in order to attend the surgery or hospital. Likewise, anxieties about

what might happen to established community care services if the regular patterns were disturbed could influence whether or not carers pursued health care in their own right.

Contributors also drew attention to the psychological barriers that could negatively affect carers' help-seeking behaviour. In their experience, many carers were unable to perceive that they themselves had needs – or indeed rights – to their own health care. Over time, carers could experience increasing social isolation that in turn could lead to a loss of focus on their own health needs. They might also see asking for help as an admission of failure, and believe they should be able to manage their care activities privately. Rural carers in small communities especially could be tempted to hide their problems. Older carers were said to find it particularly hard to delineate between their needs and those of the care recipient – and they could also suffer from an 'ageist culture' in the health service.

Contributors spoke of the specific barriers faced by those caring for a person with mental health problems. Because mental illness commonly fluctuated, carers' needs also fluctuated and could suddenly become more or less intense. Carers also knew that, if they themselves became ill, the stress of this could trigger the mental illness of the care recipient – consequently they might try to suppress their own health problems. Carers were also felt to face the additional stigma and discrimination associated with mental illness, which could be especially hard for first-time carers. Consequently, it was common to have a long period of denial before the carer sought help.

Contributors identified barriers relating to specific groups of carers. For example, young carers (and particularly those whose parents had a learning disability or mental health problem, or other stigmatising condition) were felt to face particular barriers in accessing their own health care. They were less likely than other children to be encouraged by their parent(s) to address their own health needs by seeing the GP, health visitor or school nurse or by attending routine childhood screenings or vaccinations. The parent might even avoid seeking help for the young carer for fear of being judged as a poor parent or of jeopardising the whole situation – and the child might avoid doing so out of loyalty to the parent, or simply because they failed to recognise that they could seek help. As children seldom initiated their own health care, or thought about their own health needs, it was harder for young carers than for adult carers to recognise the impacts of a stressful situation on their health. Contributors felt that if they did have a health problem, young carers were unlikely to open up to an adult unless they were sure they would be believed or understood and a relationship of trust had been established. In their experience, those professionals who did try to talk to young carers often mistakenly focused on the *tasks* the child had to do, instead of helping them to explore their *feelings* about their situation.

Carers from black and ethnic minority communities were thought by contributors to be less assertive with health care professionals. This carried the risk of staff being less likely to adopt a preventive approach. While some received support from the extended family, other carers were very isolated and unlikely to know where to go for help.

Contributors felt that some of the practical and psychological problems were even more acute for carers who were trying to balance paid work with caring, or who were caring for more than one person. These groups of carers had more calls on their time, so were even more likely to disregard their own health needs until a critical point was reached.

3.7.6 Summary and ways forward

Similar barriers to access to health care relating to the characteristics of either the carer or the care recipient emerged from relatively robust studies in the review of the literature as well as the consultation. Problems identified included: carers' approach to care giving and/or health promotion; carers' help-seeking behaviours; personal and/or cultural beliefs and preferences; care recipients' attitude.

Solutions to address these sorts of issues could begin by encouraging carers to identify their own health care needs and to ask for, and accept, professional help. Help-seeking could be improved by educating carers about the benefits of implementing effective health promotion behaviours. Local carers' organisations and/or primary care initiatives (see Chapter 4) might have a useful role in this regard. Carers' negative attitudes about respite care and short breaks could be addressed if services were offered in familiar surroundings (in their own homes, for instance). Alternatively, visits to agencies offering the relevant services to see what they offer first-hand and talking to current users might be of value.

3.8 Barriers related to knowledge and information issues

Generally, the studies reviewed related as much to the health care needs associated with the carer's caring role (for example, information about available services and how to access them, and medical information) as to their own personal needs for health care. However, it is important that knowledge-related barriers are documented; we know that information is essential for carers of all ages (Department of Health, 1999a). Indeed, carers can suffer stress and ill-health because of a lack of information about how best to help the care recipient (Department of Health, 1999a). Altogether, 16 studies identified barriers that restricted the provision of knowledge and information to carers. Problems identified included: carers not being given information about available services and how to access them, and medical confidentiality. The evidence base is stronger rather than weaker, and confirms acknowledged problem areas (Department of Health, 1999a).

3.8.1 Evidence from core studies [2;7]

The Carers UK study (Henwood, 1998) showed that carers were not being given information about local services by primary health care professionals, by hospital staff and also at critical points including when the care recipient was discharged from hospital.[2] Some carers, particularly carers for disabled children,

had particularly negative experiences of trying to get information from the NHS. Reasons given for not providing carers with information varied. It might have been because there was an assumption that carers already knew about services and support but, as the survey showed, that was not always the case. Another explanation could have been that health professionals regarded the provision of information as the responsibility of, say, social services. A minority of survey respondents reported that professional concerns about confidentiality served to restrict the medical information they were given about the health and treatment of the person supported.

Twigg and Atkin (1994) found that by putting the emphasis on patients, psychiatrists excluded mental health carers from receipt of information and contact.[7] Consultants felt they had to respect the confidences of patients, especially in those cases where the carer's role in the situation was unclear.

3.8.2 Evidence from intermediate studies [9; 10; 12; 14]

Similar issues relating to medical confidentiality were also identified in the intermediate studies. Research conducted by Arksey *et al*. (2000) showed that some carers had to deal with doctors unwilling to disclose medical information about the person supported.[9] It was a particular struggle for those who did not have the same GP, or who cared for someone experiencing mental health problems. Bibby and Becker's (2000) work on young carers suggested that the principle of medical confidentiality could sometimes be used as a shield for doctors to retreat behind and in this way avoid giving information to the young people that might have helped them in their caring activities.[14]

Another study on young carers found that carers did not want information concerning their own needs, but advice and support on care management and medical information relating to the care recipient's condition.[12] The findings showed that no young carers were provided with information or instructed about the practical aspects of caring, such as lifting techniques. Neither were they given information about welfare benefits or access to services, either for themselves or for the care recipient. Medical information was also lacking.

In the study of school nurses' support for young carers, the researcher found that school nurses had encouraged children to contact confidential telephone help-lines such as Childline, but the children reported that they found it difficult to get connected.[10]

3.8.3 Evidence from supplementary studies [15; 16; 17; 18; 20]

The overarching theme emerging from this group of studies was that carers were not given information about the availability and range of services and benefits that might have supported them in their caring role.[15; 16; 17; 20]

As far as medical information was concerned, a study involving lay carers of people with a terminal illness showed that information provided by health care professionals was often seen as conflicting and confusing.[18] Some carers felt they had been kept uninformed about particular aspects of the care of the

person supported; they commented on the use of technical terms or medical jargon that they could not understand.

3.8.4 Evidence from respite studies [22;23;25;31;32]

A lack of knowledge about respite and other services was reported in one study of ethnic minority carers of people with learning difficulties.[22] Many of these carers were women who were housebound and isolated from information and services (see also language/cultural barriers, above). Similar findings were reported in a study of ethnic minority carers of older people.[25] A study of Asian carers of people with dementia reported a lack of knowledge about the nature and type of respite services available and how to access services. Furthermore, the concept of respite was unfamiliar, and the notion of a break from caring not understood.[32]

A study of dementia carers in Australia reported that carers left to contact referral agencies themselves sometimes contacted the wrong agency.[23] The same study also reported that carers were uncertain about the diagnosis of dementia, and thus did not know if their relative qualified for support. In another Australian study, doctors said that they did not know what support was available for carers of dementia sufferers.[24]

Health care providers in a Canadian study pointed to the paucity of information on available services and a lack of awareness of the importance of using them to prevent burnout.[31] Thus, carers and other family members did not know about respite and how they might benefit.

3.8.5 Evidence from consultation

Contributors pointed out that many carers were simply unaware of the existence or relevance of the services that might be available to help them. This was a major barrier to accessing health care services. For those carers who did access services, the issue of medical confidentiality could emerge. Professionals tended to take a narrow view of confidentiality, leaving the carer feeling excluded and isolated.

3.8.6 Summary and ways forward

To repeat, problems identified in the research reports and consultation included: carers not being given information about available services and how to access them; medical confidentiality. The evidence is drawn from relatively strong studies.

Effective solutions involve providing both professionals and carers with up-to-date, comprehensive information about available services – both locally and nationally – and how to access them. A variety of languages and media will be required to best address carers' information needs. Medical confidentially issues could be addressed through advanced directives and other similar initiatives. Further research specifically into the area of information sharing between professionals and carers has recently been commissioned by the SDO programme, and is due to be completed in March 2004.

3.9 Conclusion

This chapter has reviewed evidence from primary studies reporting on carers' access to, and use of, health care services, respite and short breaks. This material has been presented in combination with data from the consultation with experts in the field. Taken together, the empirical evidence and the expert opinion present a wide range of perspectives about access problems in a variety of settings for different types of carers supporting care recipients with a range of impairments. As we found in a previous scoping study (Arksey *et al.*, 2002), the consultation was valuable in that contributors' comments strongly endorsed the findings from the review of the literature, confirming that the difficulties documented in the research articles still prevail.

As noted at the start of the chapter, there is a dearth of evidence about carers' access to health care in their own right. Moreover, what does exist is variable in terms of research design and quality. This is an important caveat that needs to be borne in mind in terms of what can be confidently concluded on the basis of the evidence available. We have made attempts to indicate the strength of the evidence base for each of the five different types of barriers that carers confront. This showed that the evidence on language or cultural issues was particularly weak relative to the other types of barriers. Comparatively speaking, the soundest evidence related to the behaviours and characteristics of professionals and how these phenomena could serve to induce barriers to health care for carers.

Overall, the evidence shows that carers confront a range of barriers when trying to access services to maintain or improve their health; obstacles occur not only at entry points, but also when someone is in the system (Rosen *et al.*, 2001). The barriers related to professionals, carers themselves and to a lesser extent care recipients. Other barriers arose from service and organisational features, language or cultural issues, and the provision of information. The available evidence does not allow us to weight the five different types of barrier against one another with any authority, or to rank them in order of severity or intensity. In any case, carers are heterogeneous; consequently, particular groups of carers will experience different barriers to varying degrees (see below).

Carers are one specific group of health care service users. The evidence illustrates how carers experience a range of general barriers that have the potential to prevent not only carers but also all other patient population groups from accessing health care. These relate to: inconvenient appointment systems and 'gate-keeping'; poor consultations; reactive rather than proactive professionals; inadequate translation services; physical accessibility; transport; and cost.

However, the review and consultation also found that carers faced additional barriers to gaining access to health care, over and above those experienced by patients who were not carers. These barriers include:

- professional lack of awareness about carers' issues and the impact of caring on carers
- professional uncertainty about roles and boundaries
- professional conceptualisations, models or stereotypes about carers
- carers not being identified as carers; notes not being tagged
- concentration on the care recipient at the expense of the carer
- lengthy waiting times and appointment systems unable to accommodate restrictions related to caring
- problems relating to carers being unable to leave the home
- cost (for services and/or substitute care)
- language barriers, and use of interpretation services
- culturally insensitive services for carers (e.g. in relation to consultations and respite care)
- carers' approach to caregiving and/or health promotion
- carers' help-seeking behaviours
- carers' personal barriers, such as strong commitment to caring responsibilities, reluctance to disclose problems and perceived needs, and isolation
- lack of information about potentially relevant support services and how to access them
- medical confidentiality.

Furthermore, it is apparent that specific sub-groups of carers can face additional barriers. For instance, young carers are known to be a 'hard-to-reach' group and are particularly at risk of being overlooked by professionals and not recognised as young carers. Carers from ethnic minority communities can experience additional language and communication barriers, culturally insensitive professionals/services and implicit or explicit racism. Recent immigrant and refugee carers may be even more disadvantaged, given their unfamiliarity with the types of services available in this country. Older carers may confront ageist attitudes from professionals, while carers of people with mental health problems can run up against medical confidentiality issues.

This chapter has made suggestions about overcoming the different types of barriers that carers confront when accessing health care. In the event, action has been taken to introduce services aimed at reducing inequalities and local variations in access. In recent years, for example, local carers' organisations have been instrumental in initiating carer support projects based in primary care settings. New communications technologies have been used to develop services that provide carers with health information and professional support without their having to leave the home. In the next chapter, we focus on interventions designed to improve accessibility for carers.

Chapter 4 Interventions to improve accessibility for carers

4.1 Introduction

This chapter focuses on the evidence from the review of the literature and the consultation about interventions with the potential to overcome barriers to health care for carers. The range of interventions focused on is narrow: primary care initiatives, community-based initiatives, home-based health care projects, and geographical information systems (GIS) software. To help set the findings into context, we first of all discuss current policy initiatives that are directly or indirectly related to access issues; the views of contributors to the consultation about perceptions of how policy is being translated into practice are also included where relevant. This leads into a report documenting how the different types of interventions offer solutions to help overcome the different types of access barriers. We complete the chapter by indicating which groups of carers may, and may not, benefit in terms of improved accessibility promoted by the different types of interventions.

4.2 Current policy and practice in the NHS

The findings from the literature review and consultation set out in the previous chapter show that carers' access to health care services is affected by a number of different types of barriers. Some of these barriers relate to the way in which health care services are delivered, including the actions and attitudes of those who work within them. Others relate to the characteristics, circumstances and perceptions of the carer and the care recipient. If carers' access to health care services is to be improved, interventions need to address the full range of barriers encountered. The findings from the literature review and the consultation suggest that in terms of both current policy and current practice this is not happening.

Since the publication of the NHS Plan, 'access' has increasingly taken on a specific meaning within the NHS (Department of Health, 2000a). Initiatives being developed under the government's Waiting, Booking and Choice strategy are intended to reduce waiting times, improve appointment systems, and give patients greater choice over when and where they are seen or treated. For example, in secondary care the NHS Plan requires that by 2005 all trusts must be able to offer patients a choice of dates for all elective procedures (Department of Health, 2000a). In primary care, all GP practices will be required by 2004 to offer their patients an appointment with a GP within 48 hours.

This specific interpretation of access, as being primarily about service issues – specifically, the way the service is organised or delivered – is reinforced by the

approach adopted by the Modernisation Agency, one of the key bodies helping Trusts to improve 'access'. Within the Modernisation Agency, the National Booking Programme – Access, Booking and Choice – focuses on improving appointment booking systems, particularly for elective services; the National Primary Care Development Team focus on access in primary care and redesigning pathways to secondary care. More generally, the emphasis within the Agency is on improving the whole system. A whole-system approach encourages health care bodies to change their systems, procedures and approaches to improve the 'absolute' level of access, rather than focusing on improving 'relative' access. Relative access relates to the relative levels of access experienced by different population groups or areas, and is a course of action that runs the risk of disadvantaging those groups who are not selected for special consideration. This tension reflects the long-standing debate about universalist and selective services, and the challenge of developing the appropriate infrastructure of universalist services in order to provide a framework to develop selective services targeted at those whose needs are greatest (Titmuss, 1968).

Common sense suggests that these universal or generic initiatives to improve access are likely to benefit carers in general. This was certainly the perception of contributors to the study. Anecdotal evidence from the evaluations of local projects connected with the National Booking Programme suggested that carers had found it very helpful to be able to choose a date/time for elective services including outpatients, inpatients and diagnostics. This allowed them to plan ahead and accommodate their caring commitments. The improvements to access, facilitated by the National Primary Care Development Team, had also been found to be helpful to carers as well as the wider population. They have encouraged GP practices to work towards 'Advanced Access' i.e. restructuring workload, looking at appointment systems, and balancing the number of patients who want to be seen immediately and those who want to pre-book.

Contributors also felt that other NHS-wide initiatives, in particular Walk-In Centres, Healthy Living Centres, NHS Direct and the flexibilities offered by Personal Medical Services pilots, were likely to improve access for carers. However, few if any of these national initiatives appear to be evaluating their specific impact on carers and their access to health services. Where carers *have* been involved in evaluations, this has mainly been in relation to their roles as carers for patients and not in their capacity as patients themselves. While there is a perception that these generic initiatives do improve carers' access to health care services, there is as yet no research evidence to back this up. Furthermore, because of the absence of this evidence, it is difficult to judge whether these initiatives are equally beneficial to all groups of carers or have a differential impact.

It is also important to note that these generic initiatives primarily address barriers that are associated with service issues (e.g. the convenience of an appointment time) and are likely to have relatively little impact on the other barriers identified in this study. In order to address these barriers, it is likely that initiatives or interventions will need to focus specifically on carers, or carers and other socially excluded groups. However, in general, the

contributors did not know of many relevant initiatives relating specifically to carers' access to health care, although there were many examples of projects which aimed to promote carers' health in a very broad sense – for example, by offering complementary therapies, Healing Days, support groups, training and so forth. The majority of these seemed to be instigated and even delivered from the voluntary sector, with very few coming directly out of mainstream health care organisations. There were also many examples of primary care initiatives, but again the perception of the contributors was that these appeared to be mainly instigated through the voluntary sector, and typically involved the appointment of a generic or specialist carers' worker. There were, however, a few examples of specialist nurses employed directly by PCTs (two of whom contributed to the local interviews). However, there were very few involving secondary health care. Those named included the following: discharge co-ordinators for carers; carers' clinics in hospital wards or foyers; discharge booklets for carers; and Carers' Education and Support Programme (CESP) training courses for mental health carers.

While contributors considered that there were relatively few specific initiatives, they did cite a wide range of policies under which the issue of access to health care for carers is, or could be, addressed. These included policies specifically relating to carers, such as the National Strategy for Carers (Department of Health, 1999a), the Carers Special Grant and carers' assessments, as well as broader policies such as National Service Frameworks, Health Action Zones and regeneration programmes. For older carers of people with a learning disability, the health action plans required under Valuing People were seen as offering a particularly useful vehicle for improved access. However, contributors highlighted a number of shortfalls concerning the implementation of such policies. For example, because Social Services rather than Health has the lead responsibility for carers' assessments, these often included only basic and 'unsubtle' questions about the carer's health. The NSF for Mental Health (Department of Health, 1999b) was criticised for promoting the right of carers to an assessment as opposed to actual support. This was seen as causing resentment on both sides, with staff (and carers) seeing the assessment as an additional and unproductive burden.

Finally, disappointment was also expressed at the paucity of references to carers in the new GMS contract that comes into force in April 2004. Existing systems that could provide opportunities for the identification and support of carers (such as the requirement to check the health of over-75s) were not felt to be consistently and proactively exploited.

This concludes our review of current policy and practice in the NHS, and sets the context for the remainder of the chapter which focuses on what we found regarding the potential for interventions to improve carers' access to health care. Before that, we present some outline information about the interventions to be discussed.

4.3 Interventions to overcome barriers to health care for carers

The 14 evaluation studies that successfully passed the various stages for inclusion in the final review comprise the following: primary care initiatives, home-based health care projects, and geographical information systems (GIS) software. Seven of the 14 studies used quantitative methods; four of these were experimental studies (two were randomised controlled trials, and the other two were quasi-experimental), and the remaining three were descriptive. Of the other seven studies, four used mixed methods and three used qualitative methods.

We have categorised the evaluation studies into core studies (n=9) and intermediate studies (n=5) on the same basis used in the last chapter, namely type of study and strength of evidence. Having given the matter a lot of thought, however, we decided to present the evidence from both the core studies and the intermediate studies together. This is because, in comparison with the studies reviewed in the previous chapter, they are smaller in number and more narrowly focused. Furthermore, there is considerable overlap in findings and we want to avoid too much repetition and duplication for readers. However, we do identify at the start of each section which studies we are drawing on, and whether they belong to the core or intermediary group of studies. For detailed information about the evaluations of the individual interventions, including their strengths, weaknesses and key learning points, see the supplementary report (Arksey, 2003).

4.3.1 Core evaluation studies

Nine of the studies are particularly strong; they present the best evidence and together comprise the core evaluation studies (see Table 4.1). Fuller information can be found in Appendix 11.

Table 4.1 Core evaluation studies (n=9)

ID number	Author(s)	Intervention and main aims	Research design and study typology design code
33	Naish and Benaim (1995)	*Hackney and Newham GP–Carers Project* To improve support to carers	Mixed methods B3
36	Stevens (1999)	*Paignton and Brixham GP Carers Project* To identify and support carers; to promote carer awareness	Mixed methods B3
38	Morris (2002)	*Brent Primary Care Project* To provide carers with one-to-one advice, support and training; to develop awareness of carers' issues in GP practices	Mixed methods B3
39	Brown *et al.* (1999)	*Telephone Carer Groups* To compare the impact of telephone carer groups with traditional carer groups	Quantitative methods B2
40*	Gallienne *et al.* * (1993)	*ComputerLink* To provide support to carers of people with Alzheimer's disease via ComputerLink	Quantitative methods B1
41	Magnusson *et al.* (2002)	*Telematic Inverventions* To provide direct support and information to carers and care recipients via computer technology	Mixed methods B3
43	Mahoney (2001)	*Telephone linked care* To help carers of people with Alzheimer's disease with advice and access to a support group via the telephone	Quantitative methods B1
45	John (2000)	*Mobile Therapy Unit* To relieve symptoms of stress in carers and people with dementia	Quantitative methods B2
46	Foley (2002)	*Geographical Information Systems* (GIS) To assess the potential applicability of GIS software through a study of carers and the provision of short term breaks	Mixed methods B3

* Exceptionally, our evidence about ComputerLink also draws on a further three related articles, which included more detailed information about methodology, strengths and weaknesses of the system (Brennan *et al.*, 1991; Brennan *et al.*, 1992; Bass *et al.*, 1998).

4.3.2 Intermediate evaluation studies

The remaining five studies are summarised in Table 4.2; fuller details can be found in Appendix 11. This set of studies has a relatively weaker evidence base and these comprise the intermediate studies.

Table 4.2 Intermediate evaluation studies (n=5)

ID number	Author(s)	Intervention and aim	Research design and study typology design code
34	Lloyd (1996)	*Newhaven Carers Project* To promote and protect the health of carers	Qualitative methods C1
35	Tarry (1998)	*Carers Primary Care* Project at Fairfield Surgery, Burwash To identify and assist carers	Qualitative methods C1
37	Morris (2000)	*Cornwall Carer Support Workers Service* To improve support for carers offered by primary health care practitioners	Quantitative methods C1
42	Lazarus (1998)	*Relaxation distance learning audio tape* To reduce carers' stress levels	Quantitative methods C1
44	MacDonald (1998)	*Massage for primary carers* To reduce carers' stress and fatigue	Quantitative methods C1

4.3.3 Local interventions

Contributors to the consultation were involved with eight local interventions; these are summarised in Table 4.3 (see Appendix 12 for further information). These are slightly wider in scope than those retrieved through the literature search as they also include interventions based in the community.

Table 4.3 Local interventions (n=8)

Project	Intervention and main aims
PRTC Carers Centre – Leeds Health Project	To provide free flu vaccinations
Share the Care – Lincolnshire	To devise systems for identifying and supporting carers
Spinney GP Practice – Cambridgeshire	To devise systems for identifying and recording carers
Carers Centre – Salford	To provide health checks for carers and joint holistic assessments, and to support carers to address health issues
North Devon Hospice – Barnstaple	To provide free complementary therapies to carers and patients, to run carer support groups, and to offer a bereavement service
Barnet PCT – Barnet	To provide health checks at home
Northumberland Care Trust – Northumberland	To provide individual assessments and hands-on training in the home for individual carers
North East Wales Carers Information Service (NEWCIS) – North East Wales	To encourage GP surgeries to: identify carers; tag carers' records; identify a carers' key worker; develop initiatives to support carers

4.3.4 Primary care initiatives

Given the primacy of primary care initiatives in both the review and the local interventions, it is helpful to give brief contextual information about this particular type of intervention. Primary care initiatives first emerged in the early 1990s within the context of the new community care regulations. Space restrictions prevent us from describing each individual initiative included in the review, but full details can be found in the accompanying report (Arksey, 2003). Suffice for now to say that the initiatives were typically small-scale, developmental and funded for one or two years. One study investigating the sustainability of a primary care initiative in four GP surgeries in Cornwall concluded that there had been mixed success in terms of lasting impact[37], reflecting the tension between projects with short-term funding and long-term aims. Staffing often comprises one carer support worker, working on a part-time basis. In those instances where workers are employed on a full-time basis, they often split their time between two or more different GP surgeries. Initiatives work with primary care at different levels: direct work with carers; development work with individual GP surgeries; and strategic work with primary care groups/trusts and networks.

The evaluations suggested that there was no one ideal blueprint for how primary care initiatives should be set up. On the contrary, it was important that carer support work in GP surgeries should be individually tailored to the specific practice in question, acknowledging its own particular culture and organisation. Some factors were commonly cited, however, as having the potential to make a positive difference:

- thinking small and aiming for what was achievable

- addressing issues relating to the sustainability of new systems and procedures, if development work initiated by carer support workers over a fixed time-scale was to be continued
- ensuring the appropriate professional status of the carer support worker
- giving the carer support worker a highly visible presence in the practice
- effective collaborative work between the carer support worker and (other) members of the primary health care team
- effective joint working between the primary care initiative and other organisations in the statutory and voluntary sectors, and in particular social services and the health authority (or equivalent body)
- ensuring all staff – and in particular senior GPs – should be thoroughly involved in, and committed to, the initiative in both the planning and implementation stages.

We are now in a position to draw out key points reported in the evidence about ways to overcome some of the health care barriers that carers confront. For each type of barrier, we present evidence from the review of the literature, followed by information obtained from the consultation.

4.4 Overcoming barriers related to professional characteristics

Together, the review of the literature and the consultation suggested the following solutions to try to overcome barriers arising from professionals' behaviour and characteristics: raising carer awareness among primary care team members; promoting carers as partners in caring; general practice staff taking on the role of 'champion'.

4.4.1 Evidence from the literature review (core studies [33; 36; 38; 40; 41], intermediate studies [34; 35; 37; 44])

The evidence suggests that of all the different types of interventions included in the review, primary care initiatives were the ones with the potential to overcome professional barriers because they were the ones that tried to directly address – and influence – professional ways of behaving towards, and thinking about, carers. For instance, a key priority for the carer support workers in all the initiatives was training and raising awareness about carers' issues with members of the primary health care team, with a view to encouraging positive approaches and attitudes towards carers as well as the more practical outcome of referrals to the primary care initiative itself. The evaluations indicated that in some primary care initiatives the efforts of the carer support worker had led to raised awareness among practice staff.[35; 36; 38] Even so, referrals were not always forthcoming; doctors tended to refer relatively fewer carers than other members of the health care team.[34; 36]

The Hackney and Newham GP–Carers Project had specifically tried to investigate the nature of the GP relationship with carers, noting that there could be considerable difficulty for medical professionals to work with 'lay'

carers as colleagues.[33] The Project produced a set of good practice guidelines for general practice; these drew professionals' attention to carers' wishes to be included as 'co-workers' in the care of the person supported. An expressed aim of the Cornwall Carer Support Workers Service was to ensure that GPs, primary health care teams and social services were not only more knowledgeable about carers' needs, but they also viewed them as partners in the caring process.[37]

GP practice staff willing to act as 'champions' and promote the benefits of implementing carer systems to other staff could also help change attitudes and spread good practice.[38] Those with personal experience of caring and/or a real understanding of carers' situations were more likely to be sympathetic towards implementing carer-focused systems within surgeries.[38]

Effective awareness raising has the potential to reduce stereotyping, which can be a barrier in terms of referring carers to other health care services. MacDonald's (1998) US study of home-based massage strongly recommended that individuals making referrals should not let preconceived notions about who would or would not benefit from, or accept, receipt of massage deter them from offering this treatment to carers.[44] Treatments were acceptable to, and effective with, carers over the age of 60 with or without previous experience of massage. Similar views were implied in relation to professional assumptions about carers who might or might not be interested in using computers to access information and support (see below).[40; 41]

4.4.2 Evidence from the consultation

The contributors to the consultation also stressed the importance of the relationship between carers and professionals, emphasising the value of an informal approach based on mutual respect. In some cases the quality of this relationship, or even the personality of the individual professional, was felt to be more important than the particular therapy or the structure of a service. One staff member gave carers her own home number in case of crisis, and her experience was that this was very reassuring to carers and had never been abused.

There was a strong feeling that professionals should treat carers as 'partners' in the provision of care, and as such should ensure that they were offered training similar to that available to paid staff (for example, on manual handling, dealing with aggression, and medicines management.) In secondary care, too, carers should be seen as an integral part of the team. When carers were seen as 'part of the workforce' they were automatically included in discharge planning, and might even be given priority on waiting lists for operations or physiotherapy.

Contributors noted that even small-scale projects, which did not necessarily have high take-up rates, often had the knock-on effect of raising awareness and understanding of carers among staff groups, including both PCT and Social Services. This was certainly the case in the flu vaccination project run by the Leeds Health Project, and was also felt to be particularly true of primary care initiatives, such as those run by Share the Care in Lincolnshire, Barnet PCT and

NEWCIS. One of the key benefits of the latter was felt to be that tagging carers reminded GPs and other primary care staff about who the carers were, what they could do for carers or what else could help them. As one contributor put it: 'The GPs have finally accepted that carers are part of their business.' Another project had generated a huge increase in referrals from district nurses. Such projects were therefore felt to be 'an easy way to mainstream an issue'.

4.5 Overcoming barriers related to service issues

Together, the review of the literature and the consultation suggested the following solutions to try to overcome barriers relating to service issues: developing systems for identifying carers, and tagging carers' records; introducing special appointments for carers; flexible service provision; self-referral; providing health care in the home and/or non-health venues; exploring the use of software packages to help plan service provision.

4.5.1 Evidence from the literature review (core studies [33; 38; 39; 40; 41; 43; 45; 46], intermediate studies [34; 35; 37; 44])

A key priority for all the primary care initiatives was to help surgeries implement systems to identify carers and to tag their records, in line with government requirements (Department of Health, 1998). Identification was generally acknowledged to be difficult, particularly in relation to specific groups of carers such as young carers and carers of people with mental health problems.[35] Some surgeries routinely asked whether people had a caring role at new patient registrations, over 75s and 'well person' screenings, and other standard health checks (for instance, asthma clinics).[33; 34] Asking a question about carer status on repeat prescription forms was found to be a useful mechanism to identify carers who were not registered at the same surgery as the care recipient.[33; 38] One GP practice in the Brent Primary Care Project had begun to work with a local school nurse and a carer support worker to try to make contact with young carers in local schools.[37]

Once carer status had been recorded on carers' medical records, either with stickers on paper notes or on computer records, it was important that the records were kept up to date. In some projects, a designated member of staff was given responsibility for continued ongoing maintenance of record keeping if and when the primary care initiative came to an end.[33] Having recorded carer status, it was then vital that people's anonymity and privacy were preserved.[34]

In efforts to find out how carers perceived the general practice and what they wanted the practice to give them, one surgery taking part in the Hackney and Newham GP–Carers Project had undertaken a survey and consultation with carers.[33] Beforehand, the practice gave a commitment to seriously consider the findings and to make whatever changes they felt were necessary. Another general practice involved in the same primary care initiative had introduced special 'carer health check appointments' with GPs for carers of elderly mentally ill people.[33] GPs used these appointments to check carers' weight and

blood pressure, and to review their own general health. It was also an opportunity to focus on the caring situation and carers' concerns about the person for whom they were caring.

One of the GP surgeries in the Brent Primary Care Initiative drew up a carers' register. The receptionist with responsibility for carers' issues regularly telephoned carers she had not seen or been in contact with for some time to check their situation.[38]

Interventions with the flexibility to be delivered in the home helped to overcome transport and/or respite care problems; carers who were house-bound or lived in rural areas also stood to gain. Some carer support workers visited carers in their own homes, a facility valued by those carers who did not wish to talk at the surgery. [38; 35] Massage therapists took their tables to carers' homes.[44; 45] One service arranged substitute care if the (dementia) care recipient could not be left on their own, so that the carer could take part without anxiety or worry.[45] Continuing massage sessions even after the care recipient had died, rather than bringing them to an abrupt end, could help the carer feel supported and facilitate the readjustment to their new situation.[44]

The telephone- and computer-based services provided direct access, on demand, to information, education and 'in-home' support groups, and in this way facilitated easier access to professional support. They also attempted to ameliorate inequities of access for rural carers.[39; 40; 41; 43] The ComputerLink system provided 24-hour access, allowing support to be given at any time of the day or night, often within hours of a problem being posted (as compared with a traditional support group that meets weekly).[40] Asynchronomous communication, that is not requiring the sender or recipient to be present simultaneously, meant that carers could communicate at times that were convenient to them, a feature especially helpful for those carers juggling multiple roles in relation to caring. This latter point is important; carers may not use telephone-based systems because of caregiving demands and being too busy.[43]

Finally, researchers evaluating GIS software in the East Sussex, and Brighton and Hove areas concluded that the maps produced showed how data about respite services could be analysed and used to inform future developments relating to local provision of short-term care services.[46] However, they felt that more testing was necessary to determine GIS's potential value in terms of identifying shortfalls and lack of equity across the county. Because of difficulties in integrating qualitative and quantitative data, it was not obvious that the maps really took into account carers' needs and wishes.

4.5.2 Evidence from the consultation

Contributors to the consultation stressed that, in successful initiatives, referral protocols were kept as simple as possible, and carers were generally able to self-refer to projects. Within primary care and other services, this might well imply the need for lower entry levels so that carers could access preventive rather than reactive support, for example, by the proactive offer of well-being checks (as in the NEWCIS project, Salford Carers Centre and Barnet PCT) or of

flu vaccinations (Leeds Health Project). The use of non-health venues could be less intimidating than hospitals or clinics, and more peaceful and welcoming. Flexibility was also a key factor, both with regard to opening times, and the location of service delivery. For example, services which were offered at weekends and evenings, or which offered contact with the carer in their own home, helped those who were working, who could not get out or who did not like groups. Longer consultation periods could also give carers a chance to open up and explore their situation – this was felt to be particularly relevant to primary care, where GP consultations were usually limited to an average of eight minutes. Projects such as the North Devon Hospice project chose to use non-health venues, which were felt to be less intimidating than hospitals or clinics, and more peaceful and welcoming.

Contributors confirmed the research evidence that identification and recognition of carers are a key precursor to improving access for carers to health care. A number of the 'good practice' examples focused on how this could be achieved within the NHS, and particularly within primary care (for example, the Spinney GP practice, NEWCIS and Share the Care Lincolnshire).

4.6 Overcoming barriers related to language or cultural issues

Neither the literature review nor the contributors to the consultation identified specific remedies to try to overcome access barriers relating to language or cultural issues. However, actively reaching out to ethnic minority carers through different community facilities was seen as good practice, and it was felt that positive professional attitudes had the potential to facilitate access.

4.6.1 Evidence from the literature review (core studies [33; 38])

The first point to make is that we found no reports of interventions to improve access to health care specifically for carers from black and ethnic minority groups. For instance, the primary care initiative in Hackney and Newham deliberately chose not to embark on a 'project-within-the-project' looking at how carers within a specific ethnic minority community were supported by general practice, and decided instead to note any special needs in relation to this group.[33] There was some evidence of language difficulties, and of respite services that were unacceptable because of religious and cultural needs. One interesting point noted in the report related to the dangers in assuming that a GP from the carer's own ethnic group was necessarily going to recognise that individual as a carer, or be supportive to them in that capacity.

The Brent Primary Care Project made a passing reference to the importance of actively attempting to reach carers from different ethnic minority groups, especially those who did not speak or read English as their first language.[38] Advertising through community resources, such as places of worship, post offices, local shops and papers, was suggested. The report also contained a

recommendation to establish local support groups, which utilised community resources and with an awareness of cultural diversity.

4.6.2 Evidence from the consultation

Although contributors to the consultation identified a range of barriers related to this category, they were less able to identify initiatives that had successfully overcome such barriers. There was, however, a strong view that, once again, the attitude of professionals was of paramount importance, and the suggestion that, if health professionals felt more comfortable in dealing with black and ethnic minority families (perhaps as a result of training and awareness raising) they could do more to facilitate their access to health care – or at least would be less likely to act as a barrier to it.

Contributors did draw attention to the 'Good Practice Guide' (Powell, 2001) recently produced by the Afiya Trust, which contained many suggestions for good practice in supporting carers from black and ethnic minority groups.

4.7 Overcoming barriers related to carer or care recipient characteristics

Together, the review of the literature and the consultation suggested the following solutions to try to overcome barriers relating to the characteristics, attitudes and behaviours of carers or care recipients: supportive professionals who actively encouraged carers to seek help and advice at an early stage, reinforced by written information; the use of telephone- and computer-based technology that could provide anonymity; carer support groups.

4.7.1 Evidence from the literature review (core studies [33; 36; 38; 39; 40], intermediate studies [34; 35; 37])

We know from the previous chapter that carers' (or carer recipients') personal characteristics, values and preferences can hinder access to health care. The Brent Primary Care Project found that many carers were very accepting of their situation and did not have expectations of health care professionals beyond routine appointments, obtaining prescriptions or referral to specialist medical clinics.[38] Neither did they identify with the word 'carer', instead referring to themselves as husbands, wives, sons or daughters. For them, the caring role was part and parcel of that stage in their lives, and not necessarily seen as an additional 'burden'. This reinforces the point made earlier about the importance of surgeries implementing mechanisms for identifying and/or recording carers. Health care professionals can actively contribute to the extent to which carers recognise and prioritise their own needs. One of the good practice points for general practice staff contained in the Brent Primary Care Project evaluation report reads: 'Support carers to recognise and value their own role and the need to care for themselves' (p.30).[38]

Lack of assertiveness, traditional views of deference to the medical profession, feelings of being let down by professionals who they felt should be helping them, and not wanting 'to bother' the doctor all stand in the way of carers

accessing health care.[33] In efforts to overcome some of these issues, the Hackney and Newham GP–Carers Project undertook a project where intermediaries – receptionists, in this particular instance – offered carers information and support using the carers' information resource.[33] The Project also produced a carers guide to good practice in general practice, aimed at giving carers some ideas about how GPs and other surgery staff may be a source of support. One section of the guide, called 'Getting the Ear of your GP', attempted to overcome carers' reluctance to seek professional help by saying that GPs disliked being faced with crisis situations and from this point of view it was important that carers arranged a consultation with them sooner rather than later. It also pointed out that those carers who might feel uncomfortable about approaching their GP directly should consider who else within the practice could help them.

Advocacy services were provided by carer support workers, as well as the opportunity to thoroughly talk through issues with someone independent of the personal situation. These discussions could enable carers to identify issues and solutions they might otherwise have overlooked, or considered inappropriate.[38]

Attending carer support groups, and being with others sharing similar experiences and facing like challenges, has the potential to make (some) carers feel less isolated, give them confidence, and influence their help-seeking behaviour (see Chapter 1). To this end, some of the primary care initiatives had established support groups, usually held in the surgery and run either by the carer support worker or a member of the primary health care team (district nurse, for example).[34; 35; 36; 38] These groups provided carers with opportunities for (mutual) support, advice and information. They enabled carers to obtain help for what they might have seen as non-medical matters, but which nevertheless had an impact on their health and well-being.

Carers support groups do not suit all carers, however, in some cases reflecting the commitment and time required to attend them on a regular basis. Difficulties such as transport and/or relief care might also rule out this option for a significant number of carers. Home-based interventions were useful for those carers unable to leave the house, or who found it difficult to take time off. Telephone- and computer-based technologies helped those carers who were too embarrassed or anxious to talk to health care professionals (or other carers), because these methods of communication allowed the faceless or anonymous expression of (more open) feelings.[39; 40] Likewise, carers who lacked self-confidence could readily access the information they required at the appropriate time without necessarily having to do this via a health care professional.[41] From this point of view, carers were building up their self-esteem with regard to their personal caring resources while improving their sense of well-being.

The evaluation studies showed that carers benefited practically, emotionally and financially (see below) from the services offered by all the primary care initiatives. However, there were indications that the professional background of a carer support worker could be influential in terms of their acceptability or otherwise to carers (and also to members of the primary health care team). One primary care initiative found, for example, that the professional

background of staff identified as a 'practice carers' contact' (PCC) was important in building up carers' confidence and trust with the system.[37] In one practice, the PCC was a carer herself; this was inhibiting for some carers who felt they could not share their feelings because they perceived a lack of professional expertise.

4.7.2 Evidence from the consultation

A number of those contributing to the consultation emphasised the importance of a holistic approach, which recognised and addressed carers' emotional, psychological and even spiritual needs. Some of the good practice initiatives (such as North Devon Hospice and NEWCIS) aimed to give carers a 'sense of well-being' and reduce their anxiety levels or alleviate their feelings of exhaustion. As one contributor put it: 'It is more about emotional space than health in the narrow sense.' Carers were also perceived as protecting or improving their mental health by sharing experiences, and by being given 'permission' to express their emotions in a safe, professionally managed environment (for example, Salford Carers Centre).

Most, if not all, of the projects had represented a direct response to consultation with carers and/or front-line staff (for example, Leeds Health Project). The participants felt that, by responding to carers' expressed needs and suggestions, their projects had boosted the carers' confidence in support services, and resulted in their being more receptive to other offers of help.

4.8 Overcoming barriers related to information and knowledge issues

Together, the review of the literature and the consultation suggested the following solutions to try to overcome barriers relating to information and knowledge: the provision of accurate, up-to-date information for both professionals and carers; signposting carers to relevant agencies; providing carers with the technology (either at home or in accessible community settings) and the know-how to access information for themselves; skills training (for example, in relation to lifting).

4.8.1 Evidence from the literature review (core studies [33; 36; 38; 40; 41; 43], intermediate studies [34; 35; 37])

The findings documented in the previous chapter showed that a central barrier to access to health care for carers was lack of information and knowledge on the part of both professionals and carers. In efforts to address this deficiency, the provision of information was a key feature of all the primary care initiatives included in the review. During the lifetime of some of the initiatives, information packs and directories of local and national carer support facilities were developed by carer support workers.[33; 34; 38] Ideally, these were then kept up to date either by the carer support worker, or by a nominated member of the practice staff.

Carer support workers signposted carers on to relevant agencies in both the statutory and voluntary sectors. They provided advocacy and benefit advice, and often helped carers to complete claim forms for attendance allowance in respect of the person supported.[34; 35; 37; 38] The carer support worker in one primary care initiative estimated that in monetary terms the successful claims he had been involved in amounted to well over £30,000. [35] Reported achievements of primary care initiatives included carers knowing of someone in the surgery whom they could approach for information, advice and support about their needs as carers.[36]

The report of the Hackney and Newham GP–Carers Project included a short account of the ethical issues raised by the work, namely medical confidentiality issues related to sharing information about the care recipient with the carer and sharing information about a care recipient with another doctor.[33] While the difficulties were noted, no explicit guidelines were presented.

An alternative way to provide carers (and professionals) with information was via home-based telephone- and computer-based technology. As noted earlier, the findings from these evaluations showed that it was important that preconceived notions about the type of carer who might or might not be suitable to use, or benefit from, new technology should not influence professional thinking. In the study of ComputerLink, for example, half the sample of carers were supplied with the system.[40] The short training period of about 90 minutes, by a nurse moderator, showed that inexperienced users could be taught to successfully use a computer network. The average age of carers in the experimental group (68 years) supported the assertion that there could be acceptance and use of a computer network by those who were not viewed as 'typical' computer users.

These findings were endorsed in the ACTION study.[41] The evaluation suggested that with education and support older people were able to use information and communication technology effectively. The people who made most use of the system were older, more highly educated, and more likely to have been rated as highly proficient by the trainer after the technology training session.

The findings from both studies indicated that people with a low tolerance to technical problems may be less likely to use this type of intervention. Being too busy because of caring demands was also likely to reduce usage. The evaluations did not point to their blanket use, but rather to the considered use of these technologies with individual carers and their families with a view to ensuring the positive aspects were fully realised and the negative aspects kept to a minimum.[41]

The location of computer stations that could be accessed by carers was important. If the system was placed in a less than desirable setting in the household, then it was less likely to be used.[41] The ACTION study suggested that accessible community settings included health and social care agencies, libraries, voluntary organisations and pharmacies.[41]

The evaluation by Mahoney *et al*. (2001) of telephone groups showed that these offered a method of providing information, education and support to rural and/or isolated carers that appeared to be as effective as traditional in-person on-site groups.[43] The researchers concluded that telephone groups were a cost-effective way to support carers who lived outside urban centres.

4.8.2 Evidence from the consultation

Contributors also identified as important interventions that provided carers with the knowledge and skills to care safely with the least detriment to their own health. In such projects, staff shared their knowledge with carers and were able to show them better techniques, which could protect both the carer's and the user's health. A good example of this was the Northumberland Care Trust project in which individual carers were assessed by an expert in moving and handling.

Well-networked services could also improve carers' access to health by giving carers information about the range of services, so that they would be more comfortable about accessing that help. Such information should be available at NHS premises such as surgeries. Services such as Share the Care Lincolnshire and the Spinney GP practice which had set up carer databases could then be in regular communication with the carers, bringing the information they needed into their own homes. This would be especially helpful to those who had not been seen for a long time.

4.9 Conclusion

Current NHS policy tends to emphasise a whole-system approach aimed at benefiting everyone rather than targeting specific groups with particular access problems. As noted at the start of the chapter, contributors to the consultation believed that carers stood to gain from generic services such as the National Booking Programme. However, we found no evaluations focusing specifically on carers' use of any of these various services. There was little in the literature or the consultation to indicate that steps were being taken to try to improve carers' access to hospital-based care or tertiary care. The range of interventions was fairly narrow; most were based in primary care, and involved dedicated carer support workers. Of the different types of interventions, primary care initiatives seemed to have the most potential to address the full range of access barriers that carers confront.

The strength of the evidence base in relation to the interventions reviewed was mixed. As before, it was particularly weak in relation to overcoming language or cultural influences on access problems. In comparison, the evaluations that included evidence about solutions to help overcome barriers arising from professional characteristics, and carer and care recipient characteristics, were both larger in number and stronger methodologically.

The review of the literature helped identify the potential ability of different types of interventions to address variations in access for different groups of carers. As can be seen in Table 4.2, primary care interventions appear to work

better for some groups than for others. Home-based health care projects have the potential to be useful to carers of all ages, and may be especially valuable for those living in isolated areas and/or those who find it hard to leave the house.

Table 4.4 Interventions' ability to address variations in carers' access to health care

Intervention	Types of carers who may benefit	Types of carers who may not benefit
Primary care initiatives	• carers with a visible presence in the GP surgery • older carers • 'hard-to-reach' carers • carers in need of advocacy	• young carers • carers of people with mental health problems • carers not registered at the same surgery as the person they support • carers who do not live with/geographically close to the care recipient
Home-based health care projects	• isolated carers • rural carers • carers with transport difficulties • housebound carers • carers with busy schedules • older carers • carers of any age and/or without any previous computer or massage experience • carers wanting anonymity	• 'technophobe' carers • carers who juggle full-time work with caring

It is important to consider how best to measure health outcomes related to improved access to health care. The foregoing suggests that it is easier to do this with some types of interventions than with others. For example, it was possible in the telephone- and computer-based interventions, and also the massage and relaxation tape projects, to administer pre- and post-intervention measures designed to elicit changes in carers' health status and in this way identify health gains.

It is a much more difficult task to identify and quantify to what extent and in what ways carers benefit from primary care initiatives, yet given the resource implications of establishing these developments it is important to try to establish their effectiveness and cost-effectiveness. There is anecdotal evidence to suggest that it can be cost-effective for GPs to identify and provide support for carers through their practices, because this can then result in: shorter consultations with carers; fewer inappropriate enquiries; reduced hospital admissions for carers and people supported in the community; prevention of carers' psychological and physical ill health; and reduced

prescription needs (Warner, 1999; Morris, 2002). However, until more rigorous, scientific research is undertaken, it is hard to judge.

In order to build up the evidence base, there is a need to determine what outcome measures and other types of data should be collected systematically to try to establish the effectiveness of carer support in primary care. The Paignton and Brixham GP Carers Project (Stevens, 1999), included in the review, listed the monitoring information it had to provide in order to meet its contractual agreement with Social Services.[36] In fact, statistics were recorded on 13 different activities: numbers of carers identified in GP practice; number of carers seen by carers' worker; numbers declining a visit or further contact; number of carers referred to other agencies; numbers having respite care (planned and unplanned); nature of carer's enquiry; information provided to carer; discussions on plans for future care and self-assessment; number of carer breakdowns in the practice; carers bereaved; carers who had to give up work; carers prevented from working; and carers' perceptions of their needs from the practice. Other statistics that could be recorded, and that are possibly more health focused, include prescription needs, and positive health outcomes for carers (for instance, fewer cases of stress, exhaustion or back injuries). A point worth repeating from the Paignton and Brixham evaluation (Stevens, 1999) is that without initial benchmarking in the practice concerned, effectiveness, cost-effectiveness and assessment of impact on services and referrals to other agencies is impossible to measure.[36]

Clearly, collecting and analysing such a large range of statistics has significant resource implications which may well be beyond the scope of many projects, although it might be possible for them to be reduced to a smaller number of key measures. Without this sort of evidence, though, many doctors and other health care professionals will remain sceptical of the effectiveness of primary care initiatives. The first step, however, is to identify appropriate outcome measures.

This completes the discussion about interventions to improve carers' access to health care. The final chapter draws on the findings to present a refined model of access to health care that incorporates additional issues specific to carers, and also suggests strategies to improve access and areas for further research.

Chapter 5 Discussion and conclusions

5.1 Introduction

Current policy and practice in the NHS prioritises equitable health service provision for all, patient-centred care and support for carers of sick or disabled people, or the elderly, to help them maintain their own health and well-being (Department of Health, 1997, 1999a, 2002). There is also an emphasis on a whole-system approach, which brings together a mix of people, professions, services and buildings with the common aim of delivering a range of services in a variety of settings to provide the right care, in the right place at the right time (Rogers *et al.*, 1999; Gulliford *et al.*, 2001). There is a tension between the whole system approach, however, and singling out specific groups such as carers for special attention. Putting that debate to one side, the government, in recognition of carers' vital contribution to care in the community, is committed to ensuring that health and social services help carers maintain their health. However, carers are known to experience both physical and emotional ill-health, and there is evidence that carers feel ignored and neglected by health professionals (Henwood, 1998).

The present literature review has reported what research conducted over the past 15 years has found in relation to carers' access to health care and the barriers they confront. The review has been complemented by a consultation exercise, which involved collecting information from key stakeholders with a knowledge and interest in this area. A number of common themes have emerged from the two strands of work, and what follows is based on the findings of the literature review and the views expressed by experts taking part in the consultation. Issues are discussed under the following headings:

- Summary of results
- Conceptualising access to health care for carers
- Recommendations to improve carers' access to health care
- Gaps and weaknesses in the evidence base
- Recommendations for further research
- Dissemination and implementation of research findings.

5.2 Summary of results

This study has addressed the important issue of carers' access to health care, including respite services and short breaks. This is a very complex area, for example the subject area of 'health care' is one that is ill defined. It is especially complicated in relation to carers, because carers are involved in looking after not only their own health, but also the health of the person they support. We followed an explicit search strategy to identify primary research reports and evaluations of interventions. Even so, the search yielded a vast

number of references to scrutinise. The quantity reflected the points just made, namely that 'health care' is a very broad concept and that there is a large literature about carers and health care for the care recipient, which was not the topic of interest for the present review. Consequently, the lack of distinction in these two areas made the search more problematic.

The reports that we retrieved were all checked to confirm that they met our inclusion criteria and then assessed for quality to ensure we were drawing on evidence from the most sound of available studies. A total of 46 primary reports were included in the final review, 32 identified barriers to health care while 14 focused on interventions to improve carers' access. These were categorised in terms of research design according to a formal study design typology framework (Table 3.1), which also helped us to gain a sense of their strength of evidence. An important caveat to put in place to ensure the findings of the review are not misleading is that the strength of the evidence varied. In recognition of this, we made every effort to show whether studies which were included in the review were based on stronger or weaker data. Clearly, the variable quality of the primary reports has an impact on the conclusions that can reasonably be drawn from the evidence and we have tried not to over-interpret the data.

Obstacles hindering access were multifaceted, with the potential to manifest themselves in a number of different dimensions within and between primary care and hospital-based services, doctors and other health care professionals, carers, care recipients and other family members. On the basis of existing schema and our analysis of issues emerging from the studies reviewed, we devised our own typology specifically to accommodate barriers relating to carers' access to health care. This typology contained five different component types of barrier relating to:

- professional characteristics
- service issues
- language or cultural issues
- carer or care recipient characteristics
- information and knowledge issues.

Comments made by contributors to the consultation exercise confirmed the range of access barriers identified in the literature review. While contributors did not suggest any barriers to access over and above those identified in the literature review, that people spontaneously spoke about the same ones underlined their importance and the fact that they are still in evidence. Obstacles that carers confront over and above those faced by all patient groups, and that emerged as common to both the literature review and the consultation, included:

- professional lack of awareness about carers' issues and the impact of caring on carers
- professional uncertainty about roles and boundaries
- professional conceptualisations, models or stereotypes about carers
- carers not being identified as carers; notes not being tagged

- concentration on the care recipient at the expense of the carer
- lengthy waiting times and appointment systems unable to accommodate restrictions related to caring
- problems relating to carers being unable to leave the home
- cost (for services and/or substitute care)
- language barriers, and use of interpretation services
- culturally insensitive services for carers (e.g. in relation to consultations and respite care)
- carers' approach to caregiving and/or health promotion
- carers' help-seeking behaviours
- carers' personal barriers, such as strong commitment to caring responsibilities, reluctance to disclose problems and perceived needs, and isolation
- lack of information about potentially relevant support services and how to access them
- medical confidentiality.

Particular groups of carers emerged as confronting heightened or more intense barriers. For ethnic minority carers, these are primarily to do with language and communication, and culturally insensitive services. Immigrant carers may be doubly disadvantaged because in addition they are unlikely to be familiar with what services are available. Older carers can face ageist attitudes. In contrast, young carers are not recognised by professionals; they are unlikely to be assertive in their dealings with professionals, and they may not be believed.

The available evidence does not enable us to weight the five different types of barrier against each other with any authority, or rank them in order of severity. However, our considered view is that professional barriers, and those related to service issues, cause large problems for all groups of carers. Language or cultural difficulties are a major cause of concern for black and ethnic minority carers, and immigrant carers. Lack of information on the part of both carers and health care professionals appears to be especially pertinent to onward referral to the full range of health and social care services. The principle of medical confidentiality is an issue, particularly in the case of carers for people with mental health problems and young carers. Barriers stemming from the personal characteristics of carers or care recipients are particularly problematic in relation to accessing respite care and short breaks.

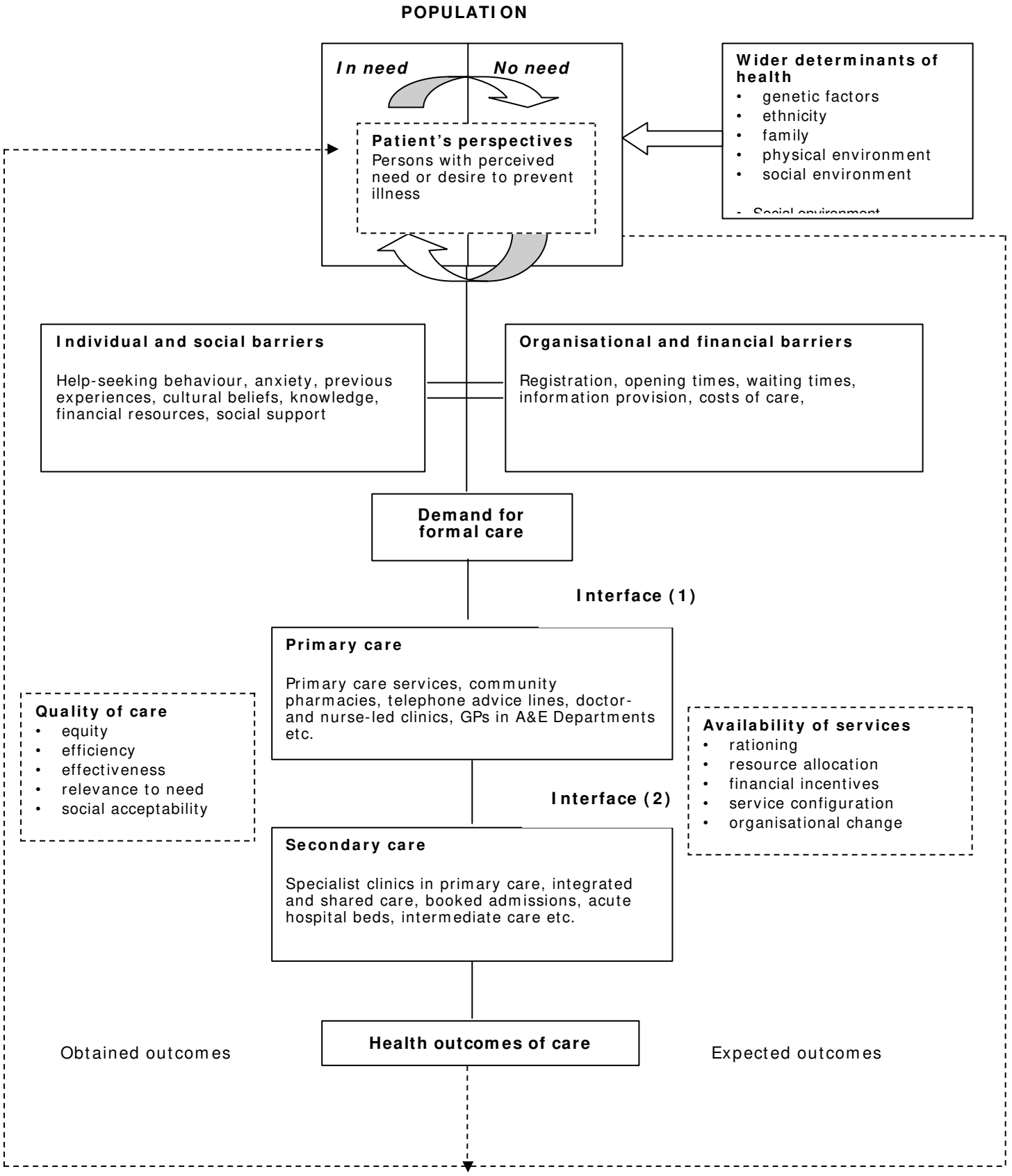
The review of the evaluations of interventions designed to improve carers' access to health care showed the potential for different types of initiative to help different types of carer (see Table 4.2 in Chapter 4). For instance, carers who stand to benefit from primary care initiatives include those with a visible presence in the surgery, older carers and 'hard-to-reach' carers. In contrast, young carers, carers of people with mental health problems and carers not registered at the same surgery as the care recipient, or who do not live geographically close to the person they support, are less likely to gain.

5.3 Conceptualising access to health care for carers

Part of the remit for the present study was to bring together theory and evidence about access to health care for carers. This is the focus of this section, and serves as a preliminary to making recommendations for strategies for policymakers and practitioners to implement to facilitate access.

The schematic diagram of access to health care presented in the SDO scoping review and reproduced in Figure 5.1 illustrates the factors that influence people's access to primary care and hospital-based services (Gulliford *et al.*, 2001: p.25). As can be seen, these include individual and social barriers, such as help-seeking behaviour, cultural beliefs and knowledge, as well as organisational and financial barriers, like opening and waiting times, and the costs of care. An individual's decision making about whether or not to try to gain access to health care is also affected by other influences, including quality of care and the availability of services. Finally, services must be relevant and effective if satisfactory health outcomes are to be achieved. The model presented by Gulliford *et al.* (2001) is useful in that it provides a starting point for understanding why people may or may not gain access to health care, and why they may or may not utilise services. It demonstrates that the concept of access is a complex one, made up of a range of different dimensions.

Figure 5.1 Schematic diagram of issues in access to health care



(Source: Gulliford et al.*, 2001: p.25)*

However, as noted in the last section, carers face additional problems over and above those that all patient groups confront; at the same time, certain groups of carers face heightened access problems. We have, therefore, refined the original Gulliford *et al*. (2001) model and produced a new version based on the evidence from the review. The refined model, shown in Figure 5.2 (p.80), is tailored specifically for carers, and incorporates the additional barriers that this group faces when accessing health care. The items in ***bold and italics*** show the additional accessibility obstacles. As well, we have repositioned the two boxes relating to 'Quality of care' and 'Availability of services' barriers so that they appear before the 'demand for formal services' stage. This is because we had concerns about the flow and temporal nature of decision-making depicted in the Gulliford *et al*. (2001) model. To us, the model presented a linear and chronological movement, suggesting that people's demand for formal health care was a result of individual, social, organisational and financial barriers. On this basis, issues relating to quality of care, and the availability of services, impinged further along the care pathway, when patients had already gained access to primary care or secondary care. Our evidence suggests otherwise, namely that carers' perceptions of the quality of care and the availability of services impact at an earlier stage – possibly while any illness symptoms are also in the process of manifesting themselves – and feed into decisions about whether or not to try to gain access to a service. We would also suggest that decision-making about accessing services can operate in a circular fashion. As carers become more knowledgeable about services and better informed about how health care systems operate (as a result, for example, of contact with a primary care initiative), they are likely to change their patterns of help-seeking and strategies to access support.

We referred briefly to research relating to carers' help-seeking behaviours

in the introduction to this report (p.3). This body of literature also has the potential to assist in conceptualising access to health care for carers. For example, according to Friedson's (1960) theoretical framework, seeking help 'involves a network of potential consultants from the intimate and informal confines of the nuclear family through successively more select, distant and authoritative laymen, until the professional is reached' (p.377). In sum, physicians are not the only source of advice about managing illness symptoms, and care in illness is embedded in family and extended networks (Stoller and Kart, 1995). As noted above, there is evidence pointing to the importance of the social network in carers' help-seeking behaviour, with professional help being sought last (Czuchta and McCay, 2001). However, it is important to avoid over-simplification: informal and formal health services operate in a complex manner, reflecting individual predispositions and variables such as age, gender and ethnicity. For instance, McEachreon *et al*. (2000) report a number of studies showing that women use significantly more formal care services than males.

There is a further body of literature that deals with concepts and issues that are also relevant to access to health care. Theories of service utilisation focus on what influences people's access to health care and how this can be improved to reduce variations. The Andersen and Newman (1973) Health

Behaviour Model is the dominant conceptual framework used to predict and explain service utilisation among the elderly (the largest users of health care). This model organises the individual factors associated with decisions to use services into three categories:

- *predisposing factors*: characteristics that predispose individuals to use a service, e.g. age, gender, education, marital status, ethnicity, occupation, health beliefs and attitudes
- *enabling factors*: facilities or circumstances that assist or impede individuals to gain access to services, e.g. structure of health care system; availability of transport; availability of service, community and family support; income; health insurance; service knowledge
- *need factors*: an individual's objective or perceived need for a service

More recently, Bass and Noelker (1987) have modified the Andersen and Newman (1973) model, by adding carers' characteristics to the predisposing and enabling factors involved in service use. The most significant divergence, however, is to incorporate need factors of the main carer into the model. Need characteristics of the carer include physical health changes and the level of activity restrictions due to caring, and a measure of carer task burden.

The predisposing, enabling and need factors of the Health Behaviour Model are reminiscent of the different barriers to access to health care for carers in the barriers typology that we developed during the course of the review (i.e. barriers relating to: professional characteristics; service issues; language or cultural issues; carer or care recipient characteristics; information and knowledge issues).

What emerges from this discussion is that there are a number of conceptual frameworks and models that each have a bearing on access issues and that could inform work specifically looking at accessibility for carers. Undertaking further work to bring these models together into a more coherent framework for conceptualising access more broadly would be useful, and have both theoretical and applied potential. For example, understanding factors that influence carers' help-seeking behaviours and encourage or inhibit them to access health services may help explain variations in health service use and facilitate (improved) identification of carers who are less likely to try to overcome obstacles to health care. It may also assist in the design and implementation of interventions targeted at carers who tend not to access health care in the presence of ostensibly high need.

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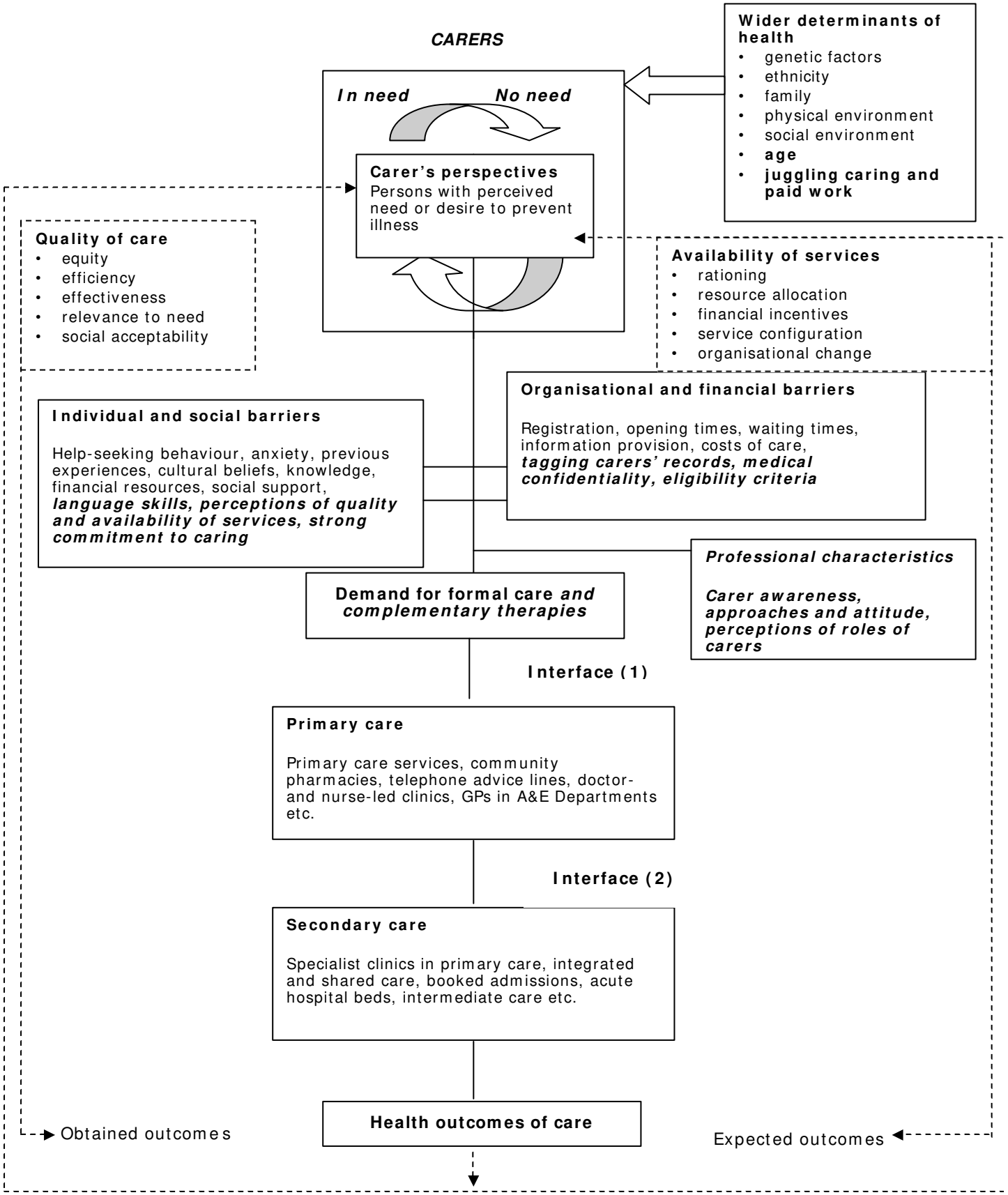
Figure 5.2 Refined model showing additional issues specifically relating to access to health care for carers



5.4 Recommendations to improve carers' access to health care

This section of the report presents our recommendations for strategies to facilitate access to health care for carers, suggestions based on the review findings and the consultation. A strength of the typology of barriers and the refined model of access to health care for carers is that they help determine access obstacles that can then be addressed by policymakers and health care practitioners to try to overcome variations in access between all patient groups and carers, and also between different groups of carers. In Chapter 3, which documented evidence about barriers to carers' access to health care, we flagged up possible solutions with the potential to improve carers' access to health care. Chapter 4 contained evidence about different types of interventions and their ability to improve access. This chapter also covered policy links in some depth (see Section 4.2), where we discussed generic initiatives such as Waiting, Booking and Choice (WBC), Walk-In Centres and NHS Direct. The WBC strategy is particularly ambitious, and is part of the NHS wider strategy to give all patients fast and convenient access to health and social care services. Pilot schemes are already offering some patients choice over which hospital they are treated in. The London Patient Choice Project, for example, offers patients who have been on a waiting list for six months the choice of having their operation at another hospital at a time and date that is convenient to them, earlier than was possible at their original hospital. Choice schemes clearly have the potential to benefit all patient groups, including carers, as they give individuals the opportunity to make choices that reflect their own priorities which might include, for instance, being treated closer to home. However, more evidence is needed if we are to understand which groups of carers benefit most, and in what ways, from generic initiatives of this type, and so understand how they could be used to greater effect for carers (see below). Furthermore, generic initiatives need to be complemented by interventions and initiatives specifically targeted on carers, if the full range of barriers to access that carers face are to be addressed.

Targeted initiatives or interventions fall into two categories. Firstly, broad carers' initiatives, such as primary care projects or carers' information services. These services are well placed to address many of the wider issues that affect access (such as identification, recognition by professionals, access to information etc.) and so they can play an important part in changing the landscape within which carers seek access to services. Secondly, initiatives that directly facilitate carers' access to health care, for example the provision of carers' health checks, priority for home visits, and the provision of flexible and appropriate respite care.

With this dual approach (generic services and targeted initiatives) in mind, the tables below set out our recommendations to increase access to health care for carers for policymakers and professionals working in different settings. They are based upon the review of the literature and the evaluations of practice interventions that identified the barriers that carers face when trying to

access health services for their own needs, and that suggested what types of interventions had some success in overcoming some of the apparent problems. The recommendations are not comprehensive as gaps were evident in the literature and good evaluations of service initiatives were scarce.

Table 5.1 Recommendations to overcome access barriers relating to professional characteristics

Recommendations	Key agencies
Pre- and post-registration training for all health professionals and front-line staff to ensure they identify and accept carers as a discrete group with their own special health needs, and adopt carer-sensitive practices as an integral part of routine patient care. Ongoing training to include changes to policy and practice initiatives and/or legislative requirements	Providers of pre- and post-registration training/primary care trusts/trusts
Initiatives and incentives to ensure professionals focus on carers' health issues	Policymakers/trusts/primary care trusts/Social Services

Table 5.2 Recommendations to overcome access barriers relating to service issues

Recommendations	Key agencies
Examine ways in which generic access initiatives could be used to greater effect for carers in general, and for specific groups of carers in particular	Policymakers
Draw up a specific national strategy for carers' health, with ringfenced funds attached	Policymakers
Produce prescriptive, evidence-based guidance on what carer support should look like, particularly in primary care; this could take the form of a booklet specifically targeted at health care professionals	Policymakers
Develop a national system for referring carers for health and well-being checks	Policymakers
Provide health care services in settings which are accessible and acceptable to carers	Primary care trusts

(Table 5.2 continued)

Lower the threshold for access to services to allow more early, preventive work with carers	Social Services/primary care trusts/ trusts/strategic health authorities
Greater recognition of the needs and special circumstances of carers in the way in which appointments and services are offered and elective procedures are arranged	Trusts/primary care trusts/strategic health authorities/GP practices
More strategic and coordinated use of the Carers Special Grant, together with careful monitoring of its use	Social Services and their partners
Increase the local availability of flexible and appropriate respite services	Social Services and their partners
Incentives for primary care professionals to focus on carers' health and proactively offer health checks	Policymakers
Identify and tag carers' medical records, including hospital admission and discharge notes	Primary care trusts/ GP practices/trusts
Inclusion of questions to identify carers in hospital admission and discharge notes	Trusts
Inclusion of a carer question at new patient registration, on regular over-75s health checks and other standard health screenings, and on repeat prescription forms	Primary care trusts/ GP practices
Identification and/or employment of a (highly visible) point of contact or carer support worker in each practice or service	GP practices/trusts
Implement tailored sets of systems for carers that suit the particular size, staff mix and working culture of individual GP practices	GP practices
Involve the local strategic health authority from the outset when initiating an intervention or innovation that may require the collaboration of primary health care teams and other local organisations	Local strategic health authority/GP practices/ primary care trusts
Provide funding for the evaluation of local initiatives to enable them to demonstrate their effectiveness	National and local funders
Recognise and address the transport needs of carers, especially in rural areas; this could include more use of home visits	Strategic health authority/primary care trusts/GP practices/ patient transport services
Develop and trial GIS software to help health care managers provide equitable service distribution according to need or demand in their geographical area	Strategic health authority/primary care trusts/trusts/Social Services
Considered use of telephone- or computer-based support in the home to reach rural/isolated carers	Primary care trusts/GP practices/Social Services
Consider offering home-based alternative therapies, such as massage or relaxation tapes, to current carers and bereaved carers	GP practices

Table 5.3 Recommendations to overcome access barriers relating to language or cultural issues

Recommendations	Key agencies
Assistance with reading, writing and form completion	Primary care trusts/trusts
Expansion of professional interpreting and translation services within practices and services	Primary care trusts/trusts
Target carers from black and ethnic minority communities by advertising carer initiatives through community resources (e.g. places of worship, post offices, local shops and papers)	GP practices/ primary care trusts
Provide cultural diversity training for health care professionals in cultural and religious issues and appropriate practices	Primary care trusts/trusts

Table 5.4 Recommendations to overcome access barriers relating to carer or care recipient characteristics

Recommendations	Key agencies
Education for carers by health professionals and/or carer support workers about the benefits of health promotion behaviours and regular screening	Primary care trusts/primary health care teams/voluntary sector
Encourage carers to recognise and acknowledge their own caring role through discussions with professionals, proactive provision of information, and promotion of services for carers	Voluntary sector/ Social Services and health partners
Promotion of positive images of carers and disability, for example through personal, health and social education courses, and citizenship programmes in schools and the wider media	Policymakers in health and education

Table 5.5 Recommendations to overcome access barriers relating to knowledge and information issues

Recommendations	Key agencies
Introduction of initiatives and procedures designed to overcome professionals' concerns about medical confidentiality issues	Policymakers/ professional bodies/local providers
Provision for carers of medical information and current information about available services in a variety of languages and media	Trusts/primary care trusts
Access for health care professionals to up-to-date information on national and local services to assist carers	Primary care trusts/trusts/ voluntary sector

The above recommendations vary in terms of feasibility. While some may be relatively easy and inexpensive to implement, those which require cultural change relating to the embedded attitudes of some health professionals will be much more difficult to achieve and are clearly long-term rather than short-term measures. Likewise, some of carers' internal barriers may be difficult for health professionals to overcome, tied up with people's feelings and family, roles and the like. Even with adequate resources, some of the recommendations will be difficult to achieve and from that point on view represent an ideal to strive towards. Some of the structural barriers will need to be addressed at the health system level, while other recommendations will require partnership working between health care and other agencies (such as education, transport, social services, or the voluntary sector). Finally, as the report for SDO by Rosen *et al*. stresses (2001), to ensure *effective* care, it is essential that the access agenda is linked to initiatives to improve the clinical quality of care.

5.5 Gaps and weaknesses in the evidence base

On the basis of this work, we have identified gaps in the topics covered in the literature as well as weaknesses in the design, methods and reporting of studies, as discussed below.

5.5.1 Gaps

The first point to make is that there is a dearth of literature focusing on the issue of access to health care for carers in their own right. Furthermore, the majority of what does exist concentrates on accessibility issues relating to primary health care. Based on the results of the review and the consultation, we have identified the following deficiencies in the literature about carers' access to:

- hospital-based care
- tertiary services
- continuing access from primary to secondary care
- national screening programmes such as breast cancer
- chiropody
- dental services
- optical care.

As noted earlier, the work shows that researchers have concentrated their efforts on inquiries into services and interventions specifically targeting carers. This has been at the expense of investigating national screening programmes aimed at both women and men, and generic services such as NHS Direct or Walk-In Centres to try to determine what impact these have on carers' access to health care. Consequently, we know nothing about carers' use of mainstream initiatives designed to improve access for all patient groups such as:

- NHS Direct
- NHS Direct Online
- Walk-In Centres
- Healthy Living Centres
- Advanced Access in primary care
- National Booking Programme.

Little, if any research, has been undertaken looking at access issues in relation to particular groups of carers, with the result that not a lot is known about how the different types of barriers to access are experienced by different types of carers. For example, common sense suggests that barriers that make access to health care (more) difficult will be different for young carers than for, say, elderly spouses caring for people with dementia living in rural areas. It is important to tease out these differences when trying to improve access to health by implementing a generic 'one size fits all' approach. As Chapter 4 showed, for instance, primary care interventions are likely to serve the interests of some groups of carers better than others. While singling out particular carer groups runs the risk of assumptions being made that all other groups are covered, it is the case that little is written in the literature specifically about access issues for the following groups:

- young carers
- older carers
- black and ethnic minority carers
- immigrant carers
- rural carers
- carers of people with mental health problems and other stigmatising conditions such as HIV/AIDS, or drug-related or alcohol problems.

A further weakness of the evidence base relates to language or cultural issues, and how these phenomena impact on carers' access to health care. To recall, this topic area was not covered in any of the core studies, or indeed the intermediate studies, reviewed in Chapter 3. Neither did we find any evaluations of interventions that specifically addressed language or cultural issues.

5.5.2 Methodological and quality issues

As highlighted in the methods chapter (Chapter 2), some studies were excluded from the final review because of issues to do with quality. There were weaknesses even within the studies we did include, which served to reduce the strength of the evidence base. We discuss these now in terms of: design issues; theoretical frameworks; outcome measures; and the reporting of research. Under each heading, we make suggestions for improvements aimed at improving the quality of research in this area.

Study design

The 46 studies included in the review used a range of research designs. Seventeen of the 46 were quantitative; just four of these were experimental (two were randomised controlled trials, and two were quasi-experimental studies). All four were evaluations of home-based health care interventions. The remaining 13 quantitative studies were descriptive, collecting quantitative data generally through postal surveys and structured interviews. Out of the rest of the 46 studies, 16 were qualitative studies and 13 were mixed-methods studies.

Most of the studies in the review drew on evidence that was cross-sectional, by way of either survey or qualitative interviews. This is satisfactory for work that is exploratory in nature. However, because cross-sectional research designs provide snapshots of the phenomenon under investigation at one point in time, it is not possible to gauge any long-term effects. Unfortunately, there was a lack of prospective studies following a group or cohort of carers through caring pathways with long-term follow-up, collecting both qualitative and quantitative data aimed at capturing both process and outcomes information.

Further weaknesses in studies included small sample sizes and not analysing findings in sufficient detail in order to distinguish between carers' and care recipients' views; access to health care for carers or care recipients; health care services or social care services. A particular weakness of one or two of the evaluations of local interventions was that they tended to include a fairly large audit and statistical element with limited analysis and interpretation of the findings. This is likely to reflect the fact that many interventions comprise pilot or development projects financed by short-term or time-limited funding. Rigorous evaluations necessitating both time and money are frequently beyond the scope of such projects, yet building in an evaluative element at the initial stage would help planners assess their effectiveness.

Many calls have been made for a pluralist approach to determine what constitutes good evidence in health care (Gowman and Coote, 2000; Marks and Godfrey, 2000). However, this review has identified a need to strengthen the evidence base relating to access to health care for carers. Study designs with high internal validity, such as experimental designs, would be valuable in demonstrating the effectiveness of interventions if random allocation is feasible, comprehensively understood and acceptable to programme participants whether the unit of randomisation is carers or the health setting. However, attention would have to be paid to gathering process information in order to assess the generalisability of the findings to other settings.

Alternatively, implementing other types of prospective study designs that might be comparatively less precise in their conclusions would nonetheless improve the evidence base for effective interventions. Such designs might, for example, collect baseline data, include long-term follow-ups, gather both outcomes and process information by way of both quantitative or qualitative data collection methods, and possibly include comparison to other groups of carers or patients.

Studies using mixed methods collecting both quantitative and qualitative data would also improve the research base. The quantitative element could provide measures of carers' use of generic services such as NHS Direct or primary care initiatives. At the same time, the qualitative data could provide depth information about exactly how and why the intervention in question improved access (or not, as the case may be), and for which particular group of carers. Study samples that included health care professionals would help to capture the full range of perspectives, and contextualise findings.

Although we did not specifically set out to retrieve economic literature, it would have been expected that the search strategy and the databases employed would have identified a portion of the economic evaluations. However, very few studies did contain an economic component. To address this gap, economic evaluations should be conducted alongside access and/or intervention studies, with economic and effectiveness data collected at the same time. Until rigorous effectiveness and cost-effectiveness research is undertaken, the long-term outcomes of supporting carers to access health care, and the potential of support for carers, remains unknown.

Theoretical frameworks

Few of the studies included in the review were grounded in any sort of theoretical framework about access to health care, although a very small minority did use their own findings to develop conceptualisations about relationships between carers and (health) professionals (Twigg and Atkin, 1994; Ward-Griffin and McKeever, 2000). Exceptionally, two studies (Chang *et al.*, 2001; Sisk, 2000) drew on Pender's Health Promotion Model (Pender, 1996; Pender *et al.*, 2002). This conceptualisation suggests that several cognitive–perceptual factors determine whether a person attends to his or her own health needs including: importance of health; perceived control of health; perceived benefits and perceived barriers. Modifying factors, including demographic and biological characteristics, and situational factors, influence these cognitive–perceptual factors. One study (Sisk, 2000) explored carer burden as a situational factor that could influence participation in health promotion behaviour.

Stress-coping frameworks based on a transactional model of stress (Lazarus, 1996; Pearlin *et al.*, 1990) have been applied to family caregiving (Nolan *et al.*, 1996; Gottlieb and Wolfe, 2002). However, none of the studies reviewed were guided by these theoretical models, which suggest that the carer's appraisal of the caregiving situation and the resources available to meet the demands will influence the choice of coping strategies and behaviour.

There are a number of conceptual frameworks that have a bearing on access issues. Work to explore if and how concepts from these various sets of literature could help inform, and further develop, theorisations about access to health care would be valuable.

Outcome measures

As noted earlier in the report, it is important to consider how best to measure health outcomes related to improved access to health care. One possibility is to use standard outcome instruments to measure levels of carer burden, strain or psychological health. In the event, very few studies used such instruments; when they were used, it was generally in the evaluation of interventions such as telephone- and computer-based projects. Here, pre- and post-interventions measures were administered in order to identify changes in carers' health status as a way to determine any health gains.

How best to measure the effectiveness of other types of interventions, such as primary care initiatives, is debatable given that it is not at all clear just what constitutes 'effectiveness'. The evaluation studies we reviewed in Chapter 4 found this a particularly challenging issue, and generally were not able to reach any firm conclusions in relation to what might be termed hard health outcomes. Given the resource implications of establishing and maintaining primary care initiatives, there is an immediate need to try to obtain some consensus from all groups of professionals about appropriate outcomes to show the effectiveness and cost-effectiveness of interventions. For example, doctors might only be interested in hard health outcomes (reduced prescription rates, say, and fewer consultations of shorter duration), whereas carer support workers might see value in softer outcome measures that are more related to preventive health care behaviours.

Reporting of research

The study design typology (Table 2.5) was useful in that it also provided a framework against which to assess the strength of the reports. Having said that, quite a number of the studies contained only brief summaries of the research methods used and the subsequent data analysis, which made the process of quality control difficult. Ideally, in these situations reviewers would contact the original author(s) to collect the unreported material (if still available), but this may not be possible in reviews working to tight deadlines. Fortunately, we were able to track down one author who sent us a copy of the primary research report. This contained far more detailed information about the research methods employed, and the results, than did the article that had been retrieved through the search. Without the full article, we might have been tempted to exclude the study from the review on the grounds that it was weak methodologically. In fact, that turned out not to be the case. This example illustrates the difficulties that reviewers face when trying to determine the quality of research. The view that a study is weak might be more a reflection of the way in which the research methods have been written up than how the research was conducted in practice. For example, the research reports' authors might have been constrained by word limits, or the particular emphases of funding bodies or journal editors, and so were unable to provide detailed accounts of the methodology adopted.

There is now a growing consensus about the need for authors of journal articles to provide more thorough accounts of the research methods adopted.

Our previous review experience (Arksey *et al.*, 2002), as well as the present study, confirms Grayson's (2003) point that more attention needs to be given to the scope, relevance and quality of abstracts. It is on the basis of the abstract that reviewers make their decisions about the initial relevance of the study to the review question and whether or not to retrieve the full article.

5.6 Recommendations for further research

On the basis of the evidence from the literature review and the consultation, we recommend that serious consideration be given to commissioning the following further research relating to carers' access to health care.

5.6.1 Carers' access to health care in their own right

The review of the literature found very few studies that focused on carers' access to health care for their own health needs. More work is needed that focuses on this particular area, and that does not confuse access issues in relation to the health care needs of carers and the health care needs of the care recipient.

5.6.2 Carers' access to health care in different settings

There is some literature about carers' access to primary health care, and the barriers encountered. However, we know very little about the problems carers as a specific group might face in other health care settings. On this basis, there is a need for primary research into carers' experiences and views about access to a wide range of health care services: hospital-based services, tertiary care, dental services, optical care, complementary therapies; national screening programmes aimed at both men and women; generic services.

Ideally, such research would evaluate the precise health outcomes of helping carers to access health care. It would also look at the impact of introducing special measures to address some of the access problems carers face. For example, does tagging carers' medical records or introducing special appointment systems for carers affect clinical management? How can a proactive approach to supporting carers improve outcomes?

5.6.3 Carers' use of generic NHS services

As just noted, the review identified a paucity of studies in relation to carers' utilisation of national screening programmes and generic services aimed at improving access to health care for all patient groups. These services include: NHS Direct; NHS Direct Online; Walk-In Centres; Healthy Living Centres; Advanced Access in primary care; and the National Booking Programme. This gap in the research base is a cause for concern. To take just one example, it is known that men and older people are less likely to use NHS Direct (Ullah, 2003). We do not know whether this is due to a lack of awareness, because they prefer to see their GP or for some other reason. When evaluations of major national initiatives are taking place, there is a need to give more attention to their utilisation by particular vulnerable groups, including carers.

5.6.4 Local primary care initiatives

The effectiveness of locally based primary care initiatives designed to improve accessibility should be monitored and evaluated, especially from the point of view of developing transferable and/or sustainable approaches. In addition, studies should be undertaken to ascertain whether such interventions help overcome obstacles for those carer groups (black and ethnic minority carers; immigrant carers; young carers; older carers; rural carers) that have been identified as confronting more intense barriers to access. Ideally, funding should be made available to set up a small number of long-term demonstration projects, which are then rigorously evaluated to determine their long-term effectiveness. If this is not possible, systematic evaluation should be built in from the start of short-term projects.

5.6.5 Culturally sensitive services

Services that were not 'culturally sensitive' were found to deter carers from trying to gain access to health care, respite and short breaks. There is a need for research to examine just what it means in reality to have 'culturally sensitive' health care services for carers, and to suggest ways of implementation.

5.6.6 Information and communication technology

Further research into carers' use of e-technologies, and in particular e-health, would be valuable especially now that NHS Direct is available online. As far as carers' access to the Internet is concerned, a new report documenting the findings of a survey carried out by the Princess Royal Trust for Carers shows that more than one-third of carers responding to a postal questionnaire could access the Internet at home or work (Keeley and Clarke, 2002). Access was greater among female carers than male carers; it decreased as age increased and as time spent caring increased. Expanding this research to obtain more detailed qualitative information about (differences in) carers' usage of the Internet could help inform the development of local, national and international e-health web sites for carers. At the same time, it would be interesting to explore the scope for local primary care initiatives, GP surgeries, hospitals and carers' organisations to work together to provide information on local, regional and national services for carers.

5.6.7 Specific carer groups

Comparative data would be valuable to show variations between geographical areas and among different groups of carers. Studies should be commissioned, for instance, that examine the extent to which young carers, older carers and carers from black and ethnic minorities experience particular barriers to gaining access and utilising health services. Further useful research would be to examine the access experiences of carers of marginalised and/or stigmatised groups, such as carers of people with mental health problems, carers of people with HIV/AIDS and carers of people with drug-related problems. The special problems of access in rural areas should be investigated.

5.6.8 Carers from refugee and asylum-seeking communities

Very little is known in general about the experiences of carers from refugee and asylum-seeking communities and now living in the UK, and in particular about their ability to access health care. New research found that disabled refugees and asylum seekers experienced barriers to accessing social services, the benefits system and social contact (Roberts and Harris, 2002). Many people taking part in that study were reliant on close family members for help with personal care such as washing, dressing and making meals. It would be most surprising if these carers did not have health problems of their own. Further research to expand the scope of the original study to encompass access to health care services for carers from refugee and asylum seeking communities would begin to address an as yet under-researched area.

5.6.9 Outcome measures

In the light of the comments we made earlier relating to the difficulties of measuring health outcomes related to improved access to health care, research aimed at reaching some agreement among different professional groups about appropriate outcome measures to help gauge the effectiveness of interventions is needed.

5.6.10 Economic evaluations

There is a lack of health economics analysis and little is known about the possible impact that barriers, or interventions to overcome them, have on costs. This gap is particularly noticeable in relation to intervention studies, for example primary care initiatives, where the resource implications are huge yet little is known about costs and/or cost-effectiveness. Economic evaluations would be valuable to policymakers interested in knowing the financial implications of interventions, and how much difference they might make.

5.6.11 Conceptual frameworks

Further work aimed at bringing together the various conceptual frameworks and models with a bearing on access issues would be valuable. Having developed a more coherent conceptual model, the next stage would be to carry out new empirical work with carers to test the value of the model with a view to refining it in the light of the findings.

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5.7 Dissemination and implementation of research findings

Finally, we are aware that the SDO programme prioritises communicating the results of research it has commissioned, and in this way supplementing the dissemination work of the researchers themselves. We recommend that continued efforts be made to improve the dissemination and implementation of existing and future research evidence, particularly the publication and wide distribution of 'reader-friendly' summaries of research. When commissioning new research, it is important for research proposals to include a well thought-out dissemination strategy, with an appropriate budget

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Appendices

Appendix 1 Electronic search strategies

The search terms were chosen to achieve an adequate balance between recall (sensitivity) and precision (specificity). The soft nature of this topic makes producing a search strategy with high precision difficult. Many of the keywords relevant to the topic have multiple meanings and/or are commonly used words in other contexts. Bibliographical details in social science databases often lack abstracts or have little or no indexing, which can restrict sophisticated searching. The search strategies are therefore as comprehensive as possible without making the number of references retrieved too great to be able to be checked for relevance in the time.

Search strategies on CD-ROMS

The Cochrane Controlled Trials Register (CCTR) (Issue 3: 2002), Cochrane Database of Systematic Reviews (CDSR) (Issue 3: 2002) and the National Research Register (NRR) (Issue 3: 2002) were all searched with the following strategy:

1 (cargiv* or care giv* or carer* or informal care or befriending):ti

2 (caretaker* or care taker* or children caring or families caring):ti

3 (((sons or daughters) or friends) near (care or caring)):ti

4 (((((((((husband* or wives) or wife) or spouse*) or grandparent*) or grandchild*) or neighbor*) or neighbour*) or relatives) and (((support or supporting) or care) or caring)):ti

5 ((((((parent or parents) or mother) or mothers) or father) or fathers) and caring):ti

6 (families near support*:ti)

7 caregivers*:me

8 1 or 2 or 3 or 4 or 5 or 6 or 7

9 (service* or support* or healthcare or care or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help)

10 (((((((utilil* or access*) or inaccess*) or barrier*) or provision) or availab*) or prohibitive) or affordability) or applicab*)

11 (#10 and #9)

12 (unmet near demand*)

13 (unmet near need*)

14 support*:ti

15 11 or 12 or 13 or 14

16 8 and 15

Search strategies on SilverPlatter

As this was not a systematic review the 'near' command was used to limit the number of references retrieved. The proximity of the 'near' commands was established by searching through 50 relevant records retrieved through a larger search.

British Nursing Index (BNI) (1994 – July 2002)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti)

22 #14 near4 (support* in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 "CARERS-" in DE

26 explode "HEALTH-PROVISION"

27 explode "HEALTH-SERVICE-PLANNING"

28 (#14 or #25) and (#26 or #27)

29 #20 or #21 or #22 or #24 or #28

CINAHL (1982–2002/07)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti ab)

22 #14 near4 (support in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 "Caregivers"/ all topical subheadings / all age subheadings

26 explode "Health-Care-Delivery"/ all topical subheadings / all age subheadings

27 explode "Health-Services-Needs-and-Demand"/ all topical subheadings / all age subheadings

28 (#14 or #25) and (#26 or #27)

29 #20 or #21 or #22 or #24 or #28

EMBASE (1980–2002/08)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 caregiver in dem

16 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

17 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

18 #16 or #17

19 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

20 #18 near7 #19

21 #14 near11 #20

22 #14 near4 (needs in ti ab)

23 #14 near4 (support in ti)

24 unmet near3 ((need* or demand*) in ti ab)

25 #24 near4 #14

26 explode "health-care-delivery"/ all subheadings in dem

27 explode "health-care-organization"/ all subheadings in dem

28 (#26 or #27) and (#14 or #15)

29 #21 or #22 or #23 or #25 or #28

Health Management Information Consortium (HMIC) (HELMIS 1984–1998, DHdata 1983–2002/07 and the King's Fund database 1979–2002/07)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti)

22 #14 near4 (support* in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 carers in de

26 service provision in de

27 needs assessment in de

28 health needs in de

29 support services in de

30 (#25 or #14) and (#26 or #27 or #28 or #29)

31#20 or #21 or #22 or #24 or #30

MEDLINE (1984–2002/08 Week 3)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti ab)

22 #14 near4 (support in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 "Caregivers"/ all subheadings in mjme

26 explode "Health-Services-Accessibility"/ all subheadings in mjme

27 explode "Health-Services-Needs-and-Demand"/ all subheadings in mjme

28 (#14 or #25) and (#27 or #26)

29 #20 or #21 or #22 or #24 or #28

PREMEDLINE (1966, August Week 3)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti)

22 #14 near4 (support* in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 #20 or #21 or #22 or #24

System for Information on Grey Literature in Europe (SIGLE) (1980–2002/06)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti ab)

22 #14 near4 (support in ti)

23 unmet near3 ((need* or demand*) in ti ab)

24 #23 near4 #14

25 #20 or #21 or #22 or #24

Sociological Abstracts (1986–2002/06)

Searched: 31/08/02

1 caregiv* in ti ab

2 care-giv* in ti ab

3 carer* in ti ab

4 informal care in ti ab

5 befriending in ti ab

6 caretaker* in ti ab

7 care taker* in ti ab

8 children caring in ti ab

9 ((sons or daughters or friends) near2 (care or caring)) in ti ab

10 families caring in ti ab

11 ((husband* or wives or wife* or spouse* or grandparent* or grandchild* or neighbour* or neighbor* or relatives) near2 (support or supporting or care or caring)) in ti ab

12 ((parent or parents or mother or mothers or father or fathers) near2 (caring)) in ti ab

13 (families near2 support) in ti ab

14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13

15 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing) in ti ab

16 (inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*) in ti ab

17 #15 or #16

18 (support* or healthcare or care or service* or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) in ti ab

19 #17 near7 #18

20 #14 near11 #19

21 #14 near4 (needs in ti ab)

22 #14 near4 (support in ti)

23 unmet near3 ((need* or demand*) in ti, ab)

24 #23 near4 #14

25 "Caregivers-" in DE

26 "Caregiver-Burden" in DE

27 #25 or #26

28 "Access-" in DE

29 "Health-Planning" in DE

30 "Health-Care-Utilization" in DE

31 "Health-Care-Services-Policy" in DE

32 "Health-Policy" in DE

33 (#14 or #27) and (#28 or #29 or #30 or #31 or #32)

34 #20 or #21 or #22 or #24 or #33

Search strategies on free Web databases

Caredata - http://www.elsc.org.uk/bases_floor/caredata.htm
Searched: 10/09/02

Two separate searches were conducted on Caredata and then the subsequent sets of results were duplicated against each other.

The first search was restricted to keywords only and searched for 'carers' and 'access to services' and retrieved 27 records. The second search was limited to title and abstract keywords and searched for:

(carer* / caregiv* / care giv* /)

&

((service* / promotion / support* / need* / demand* / healthcare / care / screening / program* / resource* / medical / treatment* / intervention* / strateg*)

&

(utili* / access* / inacces* / unmet* / barrier* / provision / availab* / prohibitive / affordability / applicab*/ support*)).

This strategy retrieved 270 hits.

Database of Abstracts of Reviews of Effectiveness (DARE), Health Technology Assessment Database (HTA) and NHS Economic Evaluation Database (NHS EED)

Searched: 12/09/02

s carer$ or care(w)giv$ or caregiv$ or informal(w)care or befriending or care(w)taker or care(w)taking or families(w)caring or children(w)caring

s (service$ or promotion or support$ or need$ or demand$ or healthcare or care or screening or program$ or resource$ or medical or treatment$ or intervention$ or strateg$)

s utili$ or access$ or inacces$ or unmet$ or barrier$ or provision or availab$ or prohibitive or affordability or applicab$

s needs/ttl or support$/ttl

s unmet(3w)(need$ or demand$)

s s2(4w)s3

s s1 and (s4 or s5 or s6)

Social, Psychological, Educational and Criminological Trials Register (SPECTRE)

http://128.91.198.137/
Searched: 10/09/02

Because this database is small and has an inflexible search interface a very simple but broad search strategy was carried out. The following terms were searched in any field and automatic truncation was in place;

carer or "care giv" or caregiv or "informal care" or befriending or "care taker" or "care taking" or "families caring" or "children caring"

This retrieved only 34 hits

Search strategies on subscription-only Web databases

Planex –
http://www.planex.ndirect.co.uk/validate2.asp?url=/default.asp
Searched: 20/11/02

A very broad search for any publications on carers was undertaken due to simple nature of the search interface:

carer* or care giv* or caregiv* or befriending or caretaker or care taker

The records were ranked by the search engine according to their potential relevance to the search query and the interface only allowed the first 300 records to be viewed. These were then sifted using a very broad inclusion criteria for any potentially relevant records. This resulted in 102 records.

Search strategies on BIDS (1985–2002/09 Week 1)

PsycINFO – http://www.bids.ac.uk/)
Searched: 11/09/02

#1 carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker* or children caring

#2 (sons or daughters or friends) near2 (care or caring)

#3 families caring

#4 (husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbor* or neighbour* or relatives) near2 (support or supporting or care or caring)

#5 (parent or parents or mother or mothers or father or fathers) near2 (caring)

#6 families near2 support

#7 #1 or #2 or #3 or #4 or #5 or #6

#8 (#7 near4 needs) in TI

#9 ((service* or support* or care or healthcare or screening or program* or promotion or medical or treatment* or resource* or intervention* or strateg* or help) near7 (utilization or utilisation or utilise or utilize or access or accessibility or accessible or accessing or inaccessibility or inaccessible or barrier* or provision or availab* or prohibitive or affordability or applicab*)) in DE,SU,TI,AB,KC

#10 #9 near11 #7

#11 (#7 near4 support*) in TI

#12 unmet near3 ((need* or demand*) in ti,ab)

#13 #7 near4 #12

#14 #8 or #10 or #11 or #13

International Bibliography of the Social Sciences (IBSS) (10 September 2002)

http://www.bids.ac.uk/
Searched: 11/09/02

Two search strategies were undertaken. The first strategy was not limited to any particular field and retrieved 60 hits:

(carer* or caregiv* or care giv*)

and

((service* or promotion or support* or need* or demand* or healthcare or care or screening or program* or resource* or medical or treatment* or intervention* or strateg*)

and

(utili* or access* or inacces* or unmet* or barrier* or provision or availab* or prohibitive or affordability or applicab*)

The second strategy was limited to the title field only and retrieved 81 hits of which two were duplicates with the first strategy;

(carer* or caregiv* or care giv*) and support*

Web of Science, Social Science Citation Index (SSCI)

http://wos.mimas.ac.uk/
Searched: 11/09/02

Two search strategies were undertaken. The first strategy was not limited to any particular field and retrieved 435 hits:

(carer* or caregiv* or care giv*) same ((service* or promotion or support* or need* or demand* or healthcare or care or screening or program* or resource* or medical or treatment* or intervention* or

strateg*) same (utili* or access* or inacces* or unmet* or barrier* or provision or availab* or prohibitive or affordability or applicab*)

The second strategy was limited to the title field only and retrieved 237 hits of which nine were duplicates from the first strategy:

(carer* or caregiv* or care giv*) and support*

Search strategies on OVID BioWeb

Allied and Complementary Medicine Database (AMED) (1985 – September 2002)

http://gateway.uk.ovid.com/
Searched: 06/09/02

1 caregiv$.ti,ab.
2 care giv$.ti,ab.
3 carer$.ti,ab.
4 informal care.ti,ab.
5 befriending.ti,ab.
6 caretak$.ti,ab.
7 care taker$.ti,ab.
8 care taking.ti,ab.
9 children caring.ti,ab.
10 ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11 ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12 ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13 families caring.ti,ab.
14 (families adj2 support).ti,ab.
15 or/1-14
16 Caregivers/
17 15 or 16
18 exp Health Services Accessibility/
19 exp "Health Services Needs and Demand"/
20 (unmet adj3 (need$ or demand$)).ti,ab.
21 ((utilization or utilisation or utilise or utilize or inaccessible or inaccessibility) adj7 (support$ or healthcare or care or service$ or screening or program$ or promotion or medical or treatment$ or resource$ or intervention$ or strateg$)).ti,ab.
22 ((access or accessibility or accessible or accessing) adj7 (support$ or

healthcare or care or service$ or screening or program$ or promotion or medical or

treatment$ or resource$ or intervention$ or strateg$)).ti,ab.

23 ((barrier$ or provision or availab$ or prohibitive or affordability or applicab$)

adj7 (support$ or healthcare or care or service$ or screening or program$ or

promotion or medical or treatment$ or resource$ or intervention$ or strateg$)).ti,ab.

24 (needs or support$).ti.

25 (or/20-24) or 18 or 19

26 17 and 25

Appendix 2 Results of databases searched

Database	Host	Dates covered	Date searched	Records retrieved
CDSR	CD-ROM	2002: Issue 3	11/09/02	11
AMED	OVID BioWeb	1985 – 2002/09	06/09/02	358
BNI	Silverplatter/ARC	1994 – 2002/07	31/08/02	192
CCTR	CD-ROM	2002: Issue 3	11/09/02	56
Cinahl	Silverplatter/ARC	1982 – 2002/07	31/08/02	1086
EMBASE	Silverplatter/ARC	1984 – 2002/08	31/08/02	1430
HMIC – King's Fund Database, HELMIS and Dhdata	Silverplatter/ARC	1979 – 2002/07	31/08/02	1729
MEDLINE	Silverplatter/ARC	1984–2002/08 Week 3	31/08/02	1098
DARE	Internet	Current	12/09/02	43*
HTA	Internet	Current	12/09/02	43*
NHS EED	Internet	Current	12/09/02	43*
Caredata	Internet	All	10/09/02	354
PsychInfo	BIDS	1985–09/2002 Week 1	11/09/02	835
Sociological Abstracts	Silverplatter/ARC	1986 – 2002	31/08/02	443
SSCI	Web of Science	1985-2002	11/09/02	435
IBSS	BIDS	10/09/02	11/09/02	79
SPECTR	Internet	17/07/2002	10/09/02	34
PLANEX	Internet	Current	20/11/02	**300
SIGLE	CD-ROM	1980–2002/06	31/08/02	59
NRR	CD-ROM	2002 Issue 3	11/09/02	233

* searched together

** interface limits to maximum of 300 records.

Appendix 3 Data extraction form

Ref ID	
Bibliographic details	
Study aims	Summarise study's aims and purpose (research question)
Study typology code	See Table 2.5
Summary study methods	Summarise the main features of the methods used, including sample sizes, setting etc.
Re-verification of inclusion criteria	
Population	*Does study include information on carers?* Yes, no, uncertain
Access	*Does study include information about interventions, barriers or facilitators of carers' access to health?* Yes, no, uncertain
Carer's own physical and mental health	*Does the study discuss the carers' own physical and mental health needs?* Yes, no, uncertain
From 1987 onwards	*Is the study published from 1987 onwards?* Yes, no, uncertain
Empirical research	*Is the study 'empirical' research?* Yes, no, uncertain
Inclusion criteria	*Inclusion criteria met?* Yes, no, uncertain
Record details for extra information	
Type of carer	Ethnic minority (EM), young (Y), rural (RU), extra resident (ER), co-resident (CR), spouse (S), range of carers (RA)
Access	*Does study include information about barriers or facilitators to other groups' access to health?*
Country	*In what country is the study based?* (United States US; New Zealand NZ; Canada CAN; England ENG, Wales WAL; Scotland SCOT; Northern Ireland NI; UK national UK; Australia AUS)
Applicable to UK health system	Yes, no, uncertain
Applicability	Record how the study is or is not applicable to the UK health system.
Type of study if not empirical	*What type of evidence is study, if not empirical?* i.e. policy document, expert opinion, descriptive report of intervention

Quality appraisal (skip if not empirical research – specify reasons for answers)	
Question (E)	*Is the research question clear?*
Theoretical perspective (D)	*Is the theoretical or ideological perspective of the author (or funder) explicit, and has this influenced the study design, methods or research findings?* i.e. consumer, feminist, economic rational, etc.
Study design (E)	*Is the study design appropriate to answer the question?*
Context (D)	*Is the context or setting adequately described?*
Sampling (E)	(Qualitative) *Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population?* (Quantitative) *Is the sample size adequate for the analysis used and has it been drawn from an appropriate population?*
Data collection (E) (when fieldwork conducted, how data collected, by whom etc.)	*Is the data collection adequately described and rigorously conducted to ensure confidence in the findings?*
Data analysis (E)	*Is the data analysis adequately described and rigorously conducted to ensure confidence in the findings?*
Reflexivity (D)	*Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?*
Generalisability (D)	*Do any claims to generalisability follow logically, theoretically and statistically from the data?*
Ethical standards (D)	*Have ethical issues been addressed and confidentiality respected?*
Quality threshold met	Yes, no, uncertain

Data extraction		
What restricts? (Barriers) *Tick which barrier and note evidence from study that supports relevant points.*		
Geographical/spatial		
Economic		
Physical		
Organisational		
Psychological		
Social		
Cultural		
Language		
Technology		
Ethical/legal		
Other ...		
What promotes? *(Facilitator: record details of whether the study informs us about organisational systems and practices that may have theoretical potential to overcome any restrictions on access.)*		
What improves? *(Interventions: provide as much information about specific intervention.)*		
Name (and place) of intervention		
Structure of intervention	*How is intervention set up, funded, which staff responsible, setting, management, location, theoretical basis?*	
Process/delivery information about intervention	*How do different stakeholders view intervention? Are there problems with staffing, funding, management. Is it acceptable to users etc?*	
Outcomes of intervention	*Has the intervention been evaluated? What outcomes measures were adopted, what were the outcomes? Were there any wanted or unwanted secondary outcomes?*	
Authors' recommendations for policy and practice		
Reviewers' comments on findings		
First reviewer initials and date		
Second reviewer initials and date checked		

Appendix 4 National and local organisations consulted

Interviews with national organisations	
Afiya Trust	Project Officer
Afiya Trust	Director
Alzheimers Society	Director of Information and Education
Carers UK	North of England Manager
Childrens Society	Coordinator for Young Carers initiative
Contact-a-Family	Information Officer
Department of Health	Policy Manager for Carers
Making Space	Director
Mencap	Special Advisor
National Booking Programme (Modernisation Agency)	Head of Strategy at the Redesign Team
National Primary Care Collaborative (Modernisation Agency)	Deputy Head of National Primary Care Development Team
Princess Royal Trust for Carers	Head of Policy
Rethink	Head of Policy and Campaigns

Interviews with local projects	
Carers Centre, Salford	Manager
Barnet Primary Care Trust	Carers Specialist Nurse
PRTC Carers Centre, Leeds	Health Project Manager
Share the Care, Lincolnshire	Manager
Northumberland Care Trust	Specialist Assessor in Moving and Handling
Spinney GP Practice, Cambridgeshire	Managing Partner
North Devon Hospice, Barnstaple	Director of Nursing
North East Wales Carers Information Service	Manager

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Appendix 5 Interview schedule for national organisations

Our definition of health care services in the context of this project is:

> ***Services provided in any setting that directly address carers' own physical and mental health needs as an individual, which may or may not relate to their role as a carer. Services may promote the health of carers or play a role in their health prevention.***
>
> ***We are interested in all parts of the health care system – from prevention and health promotion, primary and community care services, through to secondary and tertiary levels.***

Ask for brief details of their remit or experience.

In your experience, what kind of barriers do carers encounter when accessing, or trying to access, health care services?

Prompt for:

- practical and organisational barriers (e.g. distance, transport, home visits, technology, affordability, availability, times, disabled access, respite care)
- psychological and cultural barriers (e.g. identification with carer label, cultural issues, relationship with doctor, expectations, stigma, language, acceptability)

Are carers' attitudes to seeking help different to non-carers?

Does help seeking vary between different groups of carers? (e.g. non-resident carers, or when registered at a different practice)

Are you aware of particular access issues relating to specific groups of carers, e.g. rural, young or elderly carers, or carers from black and ethnic minority communities?

Can you see any similarities or differences with other patient groups who may be socially excluded?

In your experience, what sort of initiatives or service changes could or do improve carers' access to health care services? (Again, we'd like you to think about the whole spectrum of health care services.)

(Prompt for specific examples of effective interventions, e.g. carers workers in GP surgeries; priority status on waiting lists.)

Generally, do you have a sense of the extent to which health care organisations are addressing the issue of access for carers?

- If they are, under what policy initiatives are these issues being picked up?
- What level of priority does the issue have within your own organisation?

Are you aware of any initiatives or health care organisations which have attempted to address the issues of carers' access to health care? (request contact details)

Are you aware of any other initiatives not specifically designed for carers, but more generally to address the needs of socially excluded groups?

Are you aware of any 'grey' or published literature on this issue? (including local evaluations, policy reports etc. – request details)

What knowledge or information in this area would assist you in your own work?

What knowledge or information do you think would assist health care organisations in their efforts to improve carers' access to health care services?

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Appendix 6 Interview schedule for local organisations

Project details

1 Would you please describe your project/intervention?

Prompts:
- When was it set up?
- What prompted the setting up of the project/intervention?
- Who led the project/intervention?
- Who were the partners?
- How was it funded?
- What were the main activities/approaches?

2 Does the project/intervention target or seek to benefit a specific group of carers?

3 Is this initiative part of your organisation's response to a national policy?

Effectiveness and evaluation

4 What are the specific characteristics of the project/intervention which promote or improve carers' access to health?

5 Was the project/intervention designed to overcome specific barriers encountered by carers when trying to access health care services?

6 Has the intervention been evaluated or 'written up' in any way? (request copies of any relevant documentation if available, e.g. evaluations, committee reports)

7 If there has been an evaluation, what were its key findings?

8 Did it look at costs and cost-effectiveness as well as effectiveness?

9 If the project/intervention has not been evaluated, is it generally regarded as successful/effective? If so, why? If not, why not?

10 Is it regarded as cost-effective? If so, why? If not, why not?

11 Have you any other comments on the strengths and weaknesses of the project, and any key learning points for other organisations?

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Wider access issues

12 Generally, do you have a sense of the extent to which health care organisations in your area are addressing the issue of access for carers?

13 Was this project/intervention part of a wider initiative to improve access for groups who might find it difficult to make use of health care services?

and/or:
Has it influenced how access for other groups could be improved?

14 In your experience, what other initiatives or service changes could (or do) improve carers' access to health care services – whether or not they are specifically designed for carers?

15 Are you aware of any other *specific* initiatives or health care organisations which have attempted to address the issues of carers' access to health care? (if yes, request contact details)

16 If yes, under what policy initiatives are these issues being picked up?

17 Are you aware of any 'grey' or published literature on this issue? (including local evaluations, policy reports etc - request details)

18 Finally, what knowledge or information do you think would assist health care organisations in their efforts to improve carers' access to health care services?

Appendix 7 Summary of core studies (n=7)

ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
1	Simon and Kendrick (2001)	To determine current practice and views of general practitioners and district nurses on their role relating to carers	Generic	Quantative methods: postal questionnaire survey	General practitioners (n=211) District nurses (n=223)	Professional characteristics; service issues	B3	UK
2	Henwood (1998)	To examine carers' health and their experiences of the NHS	Generic	Quantative methods: postal questionnaire	Members of Carers National Association (now Carers UK) (n=3031)	Professional characteristics; service issues; knowledge and information	B3	UK
3	Sisk (2000)	To investigate whether the perception of burden is related to the health-promoting behaviours of carers of the elderly	Elderly	Quantative methods: standard outcome measures: Objective Burden Scale; Subjective Burden Scale; shortened Seriousness of Illness Rating Scale; Health-Promoting Lifestyle Profile; demographic characteristics.	Carers (n=121)	Carer or care recipient characteristics	B3	USA

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
4	Leeds Family Health (1995/96)	Report of a study of carers and primary health care in Leeds	Generic	Mixed methods: interviews, questionnaires and group discussions	Group discussions (n=5 groups) Interviews with carers (n=49) Questionnaire respondents: professionals (n=270); general practice staff (n=213)	Professional characteristics; service issues	B3	UK
5	Burton *et al.* (1997)	To seek knowledge about preventive health practices of carers	Spouse	Quantative methods: structured interviews	High-level carers with a spouse with an Activities of Daily Living impairment (n=212) Moderate-level carers with a spouse with one or more Instrumental Activities of Daily Living impairments (n=222) Control group (n=385)	Carer or care recipient characteristics	B3	USA

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
6	Ward-Griffin and McKeever (2000)	To examine the relationship between community nurses and family members providing home care to older persons in urban Canada	Elderly	Qualitative methods: in-depth focused interviews	Carer–nurse dyads (n=23)	Professional characteristics	B3	Canada
7	Twigg and Atkin (1994)	To examine how service providers like doctors, social workers and community nurses respond to carers	Generic	Qualitative methods: in-depth interviews	Carers (n=90) Service providers and managers (n=125)	Professional characteristics; carer or care recipient characteristics; knowledge and information	B3	UK

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Appendix 8 Summary of intermediate studies (n=7)

ID number	Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
8	McIntosh *et al.* (1999)	To assess whether dementia care is a stress-provoking experience and examine perceived roles, attitudes and anxieties for general practitioners and nurses working with people with dementia and their informal carers	Dementia	Quantative methods: questionnaire survey of health professionals	General practitioners (n=245) General practioner registrars (n=53) Health visitors (n=86) District nurses (n= 142) Community nurses (n=53) Community psychiatric nurses (n=206)	Professional characteristics	C1	UK
9	Arksey *et al.* (2000)	To examine the impact of the Carers (Services and Recognition) Act 1995 in four local authority social services departments in northern England	Generic	Mixed methods: interviews with carers, social services policy managers and practitioners; document analysis. Outcome measures: Carers Assessment of Difficulties Index and Carers Assessment of Satisfactions Index	Carers (n=51) Social services managers (n=5) Social services practitioners (n=16)	Professional characteristics; knowledge and information	B3	UK

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ID number	Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
10	McClure (2001)	To ascertain school nurses' knowledge and awareness of school-age caregivers	Young carers	Qualitative methods: group discussions	School nurses (n=18)	Carer or care recipient characteristics; Knowledge and information.	C1	UK
11	Chang *et al.* (2001)	To explore older carers' mammography participation and the facilitators and barriers to screening	Generic	Quantitative methods: structured telephone interviews with carers	Carers (n=52)	Service issues; carer or care recipient characteristics	C1	USA
12	Aldridge and Becker (1993)	To look at the lifestyles and experiences of young carers in Nottingham	Young carers	Mixed methods: literature review; interviews with young carers and professionals	Young carers (n=15) Professionals from health, education, social services and voluntary sectors (numbers not given)	Professional characteristics; carer or care recipient characteristics; knowledge and information	B3	UK
13	Frank (1995)	To investigate the needs of young carers	Young carers	Qualitative methods: interviews with young carers	Young carers (n=16)	Professional characteristics	C1	UK

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ID number	Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
14	Bibby and Becker (2000)	Accounts of young carers speaking directly of their experiences, their lives, their families and their relationships with adult professionals	Young carers	Qualitative methods: contacted over 100 young carers' projects asking for written accounts of life as a young carer	Exact sample size is not given, but authors selected extracts from approximately 160 contributions from young carers Also included extracts from a series of structured conversations with older young carers	Professional characteristics; knowledge and information	C1	UK

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Appendix 9 Summary of supplementary studies (n=6)

ID number	Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
15	Walters *et al.* (2001)	To explore patients' and carers' help-seeking behaviour and perceived barriers to meeting unmet needs	Elderly	Mixed methods: standard outcome measures (Camberwell Assessment of Need for the Elderly) and carers' needs assessment Semi-structured interviews	Registered patients aged 75 years and over (n=55) Carers (n=15)	Professional characteristics; service issues; carer or care recipient characteristics; knowledge and information	B3	UK
16	Ward and Cavanagh (1997)	To idenitfy carers' health and social care needs	Generic	Qualitative methods: focus group discussions	Carers (n=103)	Professional characteristics; service issues; knowledge and information	B3	UK
17	Katbamna *et al.* (1998)	To establish the nature of caring responsibilities undertaken and the impact caring had on British South Asian carers	Ethnic minority	Mixed methods: focus groups and individual in-depth interviews	Carers (n=105) from four South Asian communities: Pakistani Muslim; Punjabi Sikh; Gujarati Hindu; Bangladeshi Muslim	Professional characteristics; service issues; language or cultural; knowledge and information	B 3	UK

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ID number	Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
18	Beaver *et al.* (2000)	To provide insights into users' perspectives, their lay carers and bereaved carers on palliative care service provision	Generic	Qualitative methods: semi-structured interviews	Terminally ill patients (n=15) Carers (n=10) Bereaved carers (n=19)	Service issues; knowledge and information	B3	UK
19	Gerrish (2001)	To examine the nature and effects of communication difficulties between district nurses and South Asian patients	Ethnic minority	Mixed methods: ethnographic case study approach, including participant observation and interviews	Nurses observed (n=22), some were interviewed Nurse–patient interactions observed (n=291)	Language or cultural	B3	UK
20	Neufield *et al.* (2002)	To understand how immigrant women carers accessed support from community resources and identify the barriers to that support	Generic	Mixed methods: interviews, participant observation, focus groups	Immigrant women carers (n=29). Professionals (n=15).	Service issues; language or cultural; carer or care recipient characteristics; knowledge and information	B3	Canada

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Appendix 10 Summary of respite studies (n=12)

ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
21	Frost (1990)	To provide information on the amount of respite care provided for carers, carers' evaluations of this support and their wishes for the future development of services	Generic	Mixed methods: survey, semi-structured interviews; discussions at three conferences; written submissions from local carers' organisations	Interviews: carers (n=50) Three conferences attended by carers and service providers (n=300+) Survey: carers (n=1000 surveyed)	Service issues	B3	UK
22	Hatton *et al.* (1998)	To examine the support needs of south Asian families with a person with learning difficulties, the support received by these families and carers' ideas for improving services	Ethnic minority/ learning difficulties	Quantitative methods: structured interviews	Carers (n=54)	Language or cultural; Knowledge and information	B3	UK

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
23	Bruce and Paterson (2000)	To understand how carers of dementia sufferers gain access to community support and to determine potential barriers for carers	Dementia	Qualitative methods: semi-structured interviews	Resident carers (n=24)	Professional characteristics; carer or care recipient characteristics; knowledge and information	B3	Australia
24	Bruce *et al.* (2002)	To investigate the circumstances that lead general practitioners to refer dementia sufferers and their carers to community support services	Dementia	Qualitative methods: interviews	Resident carers (n=21) General practitioners (n=19)	Professional characteristics; service issues; carer or care recipient characteristics	B3	Australia
25	Netto (1998)	To investigate the need for, use of and preferences for respite services among ethnic minority carers of older people	Ethnic minority	Qualitative methods: interviews	Carers (n=45)	Language or cultural; carer or care recipient characteristics; knowledge and information	B3	UK

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
26	Baxter and Baxter (2000)	To study users' and carers' experience of services	Generic	Quantitative methods: structured questionnaire	Black and ethnic minority users (n=16) White users (n=11) Black and ethnic minority carers (n=10) White carers (6)	Language or cultural	B3	UK
27	Clarke and Watson (1991)	To investigate caring for a dementing person in the community	Dementia	Qualitative methods: diary, interview and post-contact	Carers (n=14)	Carer or care recipient characteristics	B3	UK
28	Cohen-Mansfield *et al.* (1994)	To examine reasons for non-utilisation of adult day care by those who inquire about the programmes but choose not to participate	Generic	Quantitative methods: structured telephone interviews with carers	Carers (n=111)	Service issues; language or cultural; carer or care recipient characteristics	B3	USA

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
29	Hayes *et al.* (1996)	To describe the characteristics of respite services across England	Learning disabilities	Mixed methods: postal survey of social services departments; visits to eight services identified as innovative	Social services respondents (n=76) Interviews with two users of each service visited, their parents, carers, support workers and service management Questionnaires to all carers and support workers in each service	Service issues	B3	UK
30	Clarke and Finucane (1995)	To undertake a needs assessment for respite for elderly (60+ years) people in receipt of care	Elderly	Quantitative methods: structured questionnaire survey	Carers (n=71). Care recipients (n=67).	Service issues; carer or care recipient characteristics	B3	Australia

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ID number	Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Study typology code	Setting
31	Morgan *et al.* (2002)	To examine dementia care	Dementia/ rural	Qualitative methods: seven focus groups for different stakeholder groups, including carers	Senior health care professionals (n=12) Nursing home staff (n=21) Nurse and home health aides (n=13) Health district board representatives (n=3) Physicians (n=7) Carers (n=13)	Professional characteristics; service issues; carer or care recipient characteristics; knowledge and information	B3	Canada
32	Godfrey and Townsend (2001)	To explore barriers to take-up of respite services for South Asian carers of people with dementia, and to examine how more culturally sensitive respite services could be developed	Dementia	Qualitative methods: in-depth interviews	South Asian carers (n=12) White carers (n=8)	Professional characteristics; language or cultural; carer or care recipient characteristics; knowledge and information	B3	UK

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Appendix 11 Summary of intervention evaluations (n=14)

Primary care initiatives (n=6)

ID number	Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
33	Naish and Benaim (1995)	Hackney and Newham GP–Carers Project To improve the amount and quality of support carers received through general practice	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Mixed methods: interviews and questionnaires	B3	UK
34	Lloyd (1996)	Newhaven Carers Project To promote and protect the health of carers	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Qualitative methods: interviews and attendance at meetings	C1	UK
35	Tarry (1998)	Carers Primary Care Project at Fairfield Surgery, Burwash To identify and assist carers	Rural	Professional characteristics; Service issues; carer- or care-recipient based; information and knowledge issues	Qualitative methods: interviews	C1	UK

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36	Stevens (1999)	Paignton and Brixham GP Carers Project To identify carers; to develop new ways of assessing carers; to develop networks and services to assist carers; to promote carer awareness within the primary health care team	Generic	Professional characteristics; service issues; information and knowledge issues	Mixed methods: interviews, questionnaires, contract documents, correspondence, minutes of meetings, interim and final reports	B3	UK

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ID number	Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
37	Morris (2000)	Cornwall Carer Support Workers Service To improve support for carers offered by primary health care practitioners	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Quantitative methods: post-intervention questionnaire survey	C1	UK
38	Morris (2002)	Brent Primary Care Project To provide carers with one-to-one advice, support and training; develop awareness of carers' issues in GP practices; support staff to implement carer-friendly systems; to develop networks with primary care managers and GP practice staff	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Mixed methods: interviews and training evaluation forms	B3	UK

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Home-based health care projects (n=7)

ID number	Author(s)	Intervention and aims	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
39	Brown *et al.* (1999)	Telephone Carer Groups To compare the impact of telephone carer groups with traditional face-to-face on-site carer groups	Rural	Service issues; Information and knowledge issues	Quantative methods: quasi-experimental	B2	Canada
40*	Gallienne *et al.* (1993)	ComputerLink (functions include communications networks, an electronic encyclopaedia, and a decision support module for carers) To provide support to carers of people with Alzheimer's disease, via ComputerLink	Alzheimer's disease	Service issues; carer or care recipient characteristics; information and knowledge issues	Quantitative methods: randomised controlled trial	B1	USA
41	Magnusson *et al.* (2002)	Telematic Inverventions (video-telephones and multimedia) To provide direct support and information to carers and care recipients via computer technology	Elderly	Service issues; knowledge and information	Mixed methods: semi-structured interviews, questionnaire, log diaries, field notes	B3	Europe
42	Lazarus (1998)	Relaxation distance learning audio tape To reduce carers' stress levels	Generic	Service issues	Quantitative methods: before-and-after study (uncontrolled)	C1	UK

* This entry draws on three other articles about ComputerLink, which included more detailed information about methodology, strengths and weaknesses of the system: Brennan *et al.* (1991); Brennan *et al.* (1992); and Bass *et al.* (1998).

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ID number	Author(s)	Intervention and aims	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
43	Mahoney (2001)	Telephone linked care To help carers of people with Alzheimer's disease manage disruptive behaviours by providing expert advice and support groups via the telephone	Alzheimer's disease	Service issues; knowledge and information	Quantitative methods: randomised controlled trial	B1	USA
44	MacDonald (1998)	Massage for primary carers To reduce carers' stress and fatigue	Generic	Service issues	Quantitative methods: before-and-after study (uncontrolled)	C1	USA
45	John (2000)	Mobile therapy unit To relieve symptoms of stress and to increase feelings of well-being among carers and people with dementia	Dementia	Service issues	Quantitative methods: quasi-experimental	B2	UK

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Geographical information systems (n= 1)

ID number	Author(s)	Intervention	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
46	Foley (2002)	Geographical information systems (GIS) To assess the potential applicability of GIS software through a study of carers and the provision of short term breaks	Generic	Service issues	Mixed methods: interviews and workshops	B3	UK

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Appendix 12 Summary of local interventions (n=8)

Project and interviewee	Interventions and aims	Barriers addressed	Start date	Lead agencies/ contact	Carer group
PRTC Carers Centre, Leeds Health Project Manager	Carers were offered free flu vaccinations. The Consultant in Public Health wrote a joint letter with the Carers Centre to carers on the database, inviting them to have a free flu jab at one of the local health clinics, in the same way as health and care staff. No additional personnel were required. Costs were minimal, i.e. cost of a mail-out to carers through the Carers Centre database, and costs of flu jabs (c. £12 each).	Service issues	Winter 2001	Leeds Health Authority (Public Health) and the five PCG/Ts Contact: Aggie Nothard (Health Project manager at Leeds PRTC Carers Centre) on 0113 245 8338 or healthproj@lchp.fsnet.co.uk	Generic
Share the Care, Lincolnshire Manager	Senior staff from Share the Care (STC) visited individual GP practice managers who had volunteered to become involved in the pilot and discussed how they could identify and support carers. Suggestions included posters or registration forms in the surgery, carer support surgeries (run by local carer support workers) perhaps once a month, tagging records etc. Each surgery then decided what it wanted to do, with support from STC. One practice tagged all carers known to them and then wrote out to them proactively. No specific funding or personnel.	Service issues Professional characteristics	2000–02 (one-year pilots in each participating surgery)	Share the Care, in collaboration with the seven PCGs (now three PCTs) Contact: Alison Brown (Lincolnshire Share the Care Manager) on 01522 554 989 or info@sharethecare.demon.co.uk	Generic

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Project and interviewee	Interventions and aims	Barriers addressed	Start date	Lead agencies/ contact	Carer group
Spinney GP Practice, Cambridgeshire Managing Partner	The main focus was on devising systems for identifying and recording carers in the GP practice. The database of carers then enabled the practice to send out regular mail-outs, publicising carers' events and services. Special events such as training on back care and health. Individual health checks for carers ('MOTs') could also be publicised in this way No personnel specifically employed. Led by carers project committee, initially comprising a carer, a GP and the managing partner, later involving other partners. No specific funding, although local practices were allocated some funding by the PCG to set up carers' registers. The surgery won £4000 p.a. for two years for its Beacon status, to disseminate lessons learnt from the project.	Service issues	1996	The Spinney Surgery, St Ives, Cambridgeshire Contact: Debbie Wheatley (managing partner) on 01480 484 000 or Debbie.wheatley@gp-d81049.nhs.uk	Generic

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Carers Centre, Salford Manager	The Carers Health Liaison Nurse, employed by PCT, does MOTs for carers and works with other practices. Can arrange a joint holistic assessment with the social worker employed at the Carers Centre. Covers a limited geographical area. Supports carers one-to-one or in groups to address broad health issues. Intends to set up peer support groups and bring in other professionals as speakers. Has linked some carers into a 'Walking for Health' group, and is planning a specific group for men, and a gardening/ handyman service. Also planning to recruit a non-qualified 'well-being adviser' to work in the community. The project was funded through the New Deal.	Service issues Carer or care recipient characteristics	October 2002	Salford Carers Centre and Salford PCT Contact: Liz Sykes (Salford Carers Centre Manager) on 0161 833 1992 or liz@salfordcarers.freeserve.co.uk	Generic
North Devon Hospice, Barnstaple Director of Nursing	A range of complementary therapies is offered free of charge to patients and families – on a needs-led basis, but typically as a course of six sessions. Therapists are employed on a sessional basis (within guidelines of Care Standards Act 2000). Therapy is offered both at Deer Park Hospice (in Barnstaple), at the local community hospitals and at home if the patient too ill to leave. The hospice also runs carers groups facilitated by a trained counsellor – and a bereavement service using trained volunteers. Sessional therapists. National Lottery Charities Board (now Community Fund) from 1999-2002.	Service issues Carer or care recipient characteristics	July 1996	North Devon Hospice Contact: Richard Kane (Director of Nursing) on 01271 344 248 or richardkane@northdevonhospice.org.uk	Carers of people receiving palliative care

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Project and interviewee	Interventions and aims	Barriers addressed	Start date	Lead agencies/ contact	Carer group
Barnet PCT, Barnet Carers Specialist Nurse	Nurse offers health checks at home, including blood pressure, back advice, flu jabs. Uses specially designed health check tool which includes a personal action plan. Also offers health promotion, information and support. Is setting up new educational programme with talks on hypothermia, keeping well, nutrition, benefits etc. Links with 'Keeping Well at Home' nurse for 75+ assessments. District nurse seconded to PCT, initially for six months, now extended annually. Promoting Independence Grant.	Service issues Information and knowledge issues	September 2002	Local authority and PCT Contact: Sally Painter (Carers Specialist Nurse) on 0208 732 6421 or sally.painter@barnet-pct.nhs.uk	Generic but excluding young carers
Northumberland Care Trust, Northumberland Specialist Assessor in Moving and Handling	Individual assessments and hands-on training in the home for individual carers. Specialist Assessor in Moving and Handling, employed by Care Trust Mainstream budget (service originally purchased by Social Services from the Health care Trust).	Information and knowledge issues	1998	Northumberland Care Trust Contact: Carole Mercer (Specialist Assessor in Moving and Handling) on 01661 832 758 or cmercer@northumberland.gov.uk	Generic but excluding young carers

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Project and interviewee	Interventions and aims	Barriers addressed	Start date	Lead agencies/ contact	Carer group
North East Wales Carers Information Service (NEWCIS), North East Wales	Raising awareness of carers' issues with all primary care providers. Provision of carer information at all primary care sites. Specific Carer Information Points set up at majority of GP surgeries. Encouraging GP practices to identify and tag patients who are carers, and to recognise the health needs of carers. Encouraging GP practices to identify a member of staff to take on role of carers' key worker to signpost carers to appropriate services. Piloting development of health checks for carers. Developing initiatives to support carers, e.g. moving and positioning training relaxation and stress management courses. Healthy Living Scheme – provision of vouchers for stress relief therapies or activities to promote health and wellbeing (e.g. aromatherapy, reflexology, gym sessions). NEWCIS: Manager and Carer Facilitator Officers from Flintshire LHG and Flintshire Adult SSD. Joint: Flintshire LHG and Flintshire Adult SSD.	Professional characteristics Service issues Information and knowledge issues	March 2001	North East Wales Carers Information Service (NEWCIS) in conjunction with Flintshire Local Health Group and Flintshire Adult Social Services Directorate Contact: North East Wales Carers Information Service on 01352 751436 or cc@newales-carers.fsnet.co.uk	Generic

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This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.

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