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## **Unpaid carers' access to and use of primary care services**

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## **Unpaid carers' access to and use of primary care services**

### **Abstract**

GPs and members of the primary care team have a pivotal role in supporting unpaid carers in their caring role and helping them to maintain their own health and well-being. This paper investigates the difference that caregiving makes to individuals' access to and use of GP and primary care services. It is based on longitudinal analysis of carers' contacts with GPs, and a review of the literature including evaluations of measures to improve primary care-based support for carers. Men increase their consultation rates with GPs when taking on a caring role. In contrast, women who look after someone in the same household and carry heavy caring responsibilities have relatively less contact with GPs than expected. According to the literature, carers report a range of difficulties accessing primary health care. A fivefold typology is described covering barriers arising from: professional responses to the carers' role, the way services are organised and delivered, language or culturally held beliefs and practices, carer or care recipient characteristics, and unmet information needs. Various measures to improve carers' access to primary care have been introduced to overcome these barriers, but robust evidence of cost and utility is required to judge their acceptability and effectiveness for both carers and GPs. Although

good practice guides, quality standards and evaluation tools are available to help improve primary care support for carers, further investigation of carers' help-seeking for health care, and the factors involved, is required to underpin the prospects for developing a genuine partnership between unpaid carers and health professionals.

Keywords: access; carers; consultation panel; GP services; literature review; longitudinal data

## **Introduction**

Most disabled and elderly people live in private households and the support they receive in the community is almost wholly provided by family, friends or neighbours (Grundy et al., 1999). In 2000, there were an estimated 6.8 million adults providing unpaid care for disabled and elderly people in Britain, including over 1.7 million who devoted 20 hours per week or more to their caring activities (Maher and Green, 2002). Most adults are involved in caregiving at one time or another and over half are likely to provide at least 20 hours care per week at some point in their adult lives (Hirst, 2002).

Since the 1980s, successive UK governments have increasingly recognised that health and social care services would struggle to cope without the contribution of unpaid carers (DH, 1990). Current policy aims to support carers in their caring role and enable them to continue caring for as long as they wish to do so. The government's strategy for carers sets out a package of measures to meet carers' needs for information, support, and help in maintaining their own health and well-being (DH, 1999).

General medical practitioners (GPs) and members of the primary care team are well placed to play a key part in supporting carers (Katbamna et al., 2002;

Simon, 2001; Simon and Kendrick, 2001). Most carers feel that GPs have a better understanding of their role than other health or social services staff (Keeley and Clarke, 2002), and GPs are widely seen as having the power to improve the quality of carers' lives (Henwood, 1998).

The new GP contract to take effect from April 2004 offers GPs an incentive to introduce systems for identifying carers and referring them for a social services assessment of their support needs. The creation of general practice and community health services through the establishment of primary care trusts was also expected to improve support for carers (DH, 1997; NHS Executive, 1998a, b). Involving local authority social services in the governance of primary care trusts, and introducing social care staff alongside GPs and primary care teams, should further boost service responses to carers' particular needs (DH, 2000; Lankshear and Hodges, 1999).

This paper investigates carers' use of and access to primary care and GP services. It draws on evidence from two new studies looking at related aspects of carers' experiences of primary care. Using different and multiple sources of data in this way can strengthen interpretability and help address different but complementary questions in a similar way to triangulation, an approach

designed for confirmation purposes (Denzin, 1970) and to enhance the completeness of findings (Jick, 1983).

The first study looked at transitions to care, and comprised secondary analysis of data from the first ten waves of the British Household Panel Survey (BHPS) covering the years 1991 to 2000. The BHPS is a general-purpose survey of the population living in a representative sample of around 5000 private households in England, Scotland and Wales (Buck at al., 2002). All adults over 16 years included in the first wave are followed and they, and each co-resident adult, are interviewed at approximately one-year intervals. Children in the original panel are also interviewed as adults on reaching age 16.

These data were organised to identify transitions into caregiving roles. Would-be carers are observed for one interview wave before providing care (c0) and in the next year (c1) when caregiving is reported. Episodes of increasing duration are observed if caregiving is reported in subsequent years (c2 to c5). Further details of the research design, survey measures and the identification of carers are given elsewhere (Hirst, 2004).



The second study focused on barriers to health care for carers, and measures to improve carers' access. A comprehensive literature review was undertaken aimed at identifying all studies published since 1987 that provided evidence about what restricts, what promotes and what improves carers' access to health care services. Searches were made of key electronic databases and the Internet, plus some hand searching, searching websites of key organisations and contacting key researchers in the field.

Studies were checked for relevance and quality. A quality appraisal tool developed by Croucher et al. (2003) was used to establish whether a study met five criteria covering clarity of research question, appropriateness of study design, adequacy of sampling strategy, robustness of data collection, and rigour of analysis. This tool was adopted as it is readily understood, easy to apply in practice, and is not resource intensive. One reviewer applied these criteria to each study; those meeting the five quality criteria were put forward for the final review. A second reviewer checked 20 per cent of these decisions. Just 20 studies, identifying barriers to carers' access to health care, and six evaluations of interventions to improve accessibility, were found to be relevant to the review and of sufficient quality. Summary details of the access studies and intervention evaluations are included in Appendix 1 and 2 respectively.

The literature review was complemented by a consultation exercise.

Contributors included policy makers 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), and local organisations that had introduced interventions to improve carers' access to health care (n=8). Full details of the methodology for both the literature review and the consultation are contained in the final report (Arksey et al., 2003).

Results from the two studies are reported below. The paper is divided into five main sections: the first summarises cross-national evidence on carers' use of GP services. In the second section, longitudinal evidence on carers' contacts with GPs is presented. The third section examines the difficulties that some carers face when accessing primary care services. Measures to improve carers' access to GP and primary care services are described in a fourth section. A final section discusses implications of the findings for policy and practice.

### **Carers' use of GP services**

The vast majority of the population consult a GP every year (Rowlands and Moser, 2002), but taking on a caring role might be expected to increase contact with GPs for three main reasons:

1. To consult about their own health problems associated with caregiving.

There is a wealth of studies which show that carers report increased rates of anxiety, depression and psychiatric illness, as well as physical injuries such as back strain associated with lifting (Brown and Mulley, 1997; Maher and Green, 2002; Schulz et al., 1990, 1995; Singleton et al., 2002).

Emotional distress and compromised immune response associated with caregiving may also increase susceptibility to physical illness (Dyck et al., 1999; Kiecolt-Glaser et al., 1991).

2. To seek practical help with their caring responsibilities, including basic nursing tasks, use of equipment, emergency and first aid; advice about welfare benefits and special aids; and referral to other service providers.
3. To seek advice and information about the cared-for person's medical condition, prognosis, medication and other treatments, as well as arrangements for hospital discharge, intermediate care, respite services and admission to institutional care.

Quantitative evidence on the extent to which carers use GP services is 'conflicting' and 'inconsistent' (Baumgarten et al., 1997; Schulz et al., 1990; 1995). Some of the ten studies reviewed by these authors found evidence of more frequent GP visits among caregivers, some found lower than expected

contact rates, and others failed to find any significant difference between caregiver and control groups in GP contact. Firm conclusions were also hampered by methodological weaknesses in the studies reviewed including: small, unrepresentative samples, absence of comparison groups, inappropriate research designs, uncontrolled confounding effects, and reliance on self-report (Baumgarten, 1989; Baumgarten et al., 1997).

Two studies that overcome many of these limitations, one set in Canada the other in Ireland, found that GP consultation rates were no higher for caregivers than for comparable non-caregivers (Baumgarten et al., 1997; O'Reilly et al., 1996). This finding is surprising because the carers presented poorer physical and psychological health than the control groups, especially those who were most heavily involved in providing care. However, both studies were based on cross-sectional surveys that would confound the considerable changes over time in carers' support needs and coping resources (Aneshensel et al., 1995). As far as is known, no study has examined the effects on GP contact of transitions into care and successive years of caregiving. This requires a prospective design with representative samples of non-carers who are followed until those who become caregivers can be compared with those who do not take on a caring role. This design was available using the BHPS, and evidence

relating carers' use of GP services to the caregiving trajectory is presented in the next section.

### **Transitions to care**

Figure 1 shows the proportion of women who contacted a GP in the year before caregiving started (c0) and during the first five years of their care episodes (c1 to c5). These findings relate to the most heavily involved carers, those who spend at least 20 hours per week looking after someone in the same household. A majority were caring for a spouse or partner (55 per cent) and most of the remainder were looking after a parent or parent-in-law (16 per cent), or a child (24 per cent). At any one time, heavily involved co-resident carers form one sixth of the carer population but they provide two-thirds of the unpaid hours devoted to caregiving each week.

It can be seen that the proportion of women carers in contact with a GP declined from 83 per cent at baseline to 66 per cent in the fifth year of caregiving. Comparable rates for women who did not take on caregiving responsibilities remained constant at 82 per cent across comparable interview waves. Statistical modelling (using logistic regression) with a matched group of non-carers shows that women who were heavily involved caring for someone

inside their own household had relatively less contact with a GP than expected. They were significantly less likely than non-carers to consult a GP between one and five times a year, and there was no difference between carers and non-carers in consultation rates more frequent than that. There is, then, no evidence that caregiving increases the extent to which women consult a GP when taking on a caring role, or as care episodes lengthen; indeed, women with heavy caring responsibilities reported fewer consultations than expected.

In contrast, men's GP contact rates increased during the first three years of caregiving, peaked at 85 per cent, and then fell to around 74 per cent in the fourth and fifth year of caregiving, just below pre-care levels (Figure 2). Across the observation period, their contact rates remained well above the constant level reported by a matched control group (66 per cent). Statistical analysis confirms that men who took on heavy caring responsibilities inside their own household were significantly more likely to contact a GP than like non-carers; they also consulted GPs more frequently during their care episodes than did non-carers across comparable interview waves.

[insert figures 1 and 2 about here]

The research also investigated the extent of contact with GPs reported by carers who provided less than 20 hours care per week or who looked after someone living in a different household. They were mostly caring for a parent or parent-in-law (45 per cent), another relative (18 per cent), or a friend or neighbour (20 per cent). No significant differences in GP consultation rates were found between these carers and a matched control group.

Taken together, the findings indicate that there is little change in GP contact rates around transitions to heavy caring responsibilities. Indeed, men's contact rates were elevated before caregiving was reported (79 v. 66 per cent in non-carers at c0), possibly in anticipation of their caring responsibilities, or because they were already providing some types of care but have not yet accepted the role of caregiver as distinct from their normal everyday activities or family obligations (Nolan et al., 1996; Parker, 1992). Taking on a caring role is rarely the discrete event or turning point implied here, but rather a process that takes place over time (Nolan et al., 1996). Methodological factors may also be implicated. The survey question about GP contact is concerned with consultations that relate to the respondent's own health. Although this would not rule out consultations that also covered the respondent's caring responsibilities,

consultations concerned solely with those matters would go unreported. If so, any effect of transitions to care on GP consultation rates would be diluted.

Nonetheless, the findings indicate that carers' use of GP services vary according to their position in the caregiving trajectory. As heavy care episodes lengthen, women's contact rates decline relative to those of non-carers whereas men's GP consultations increase. Indeed, differences in contact rates between women and men are much smaller among carers with heavy caring responsibilities than in the general population. Systematic variations over time in GP contact levels are not found in other groups of carers, whose consultation rates do not differ from those reported by non-carers.

The reduced contact with GPs reported by women heavily involved in caring for someone inside their own household is contrary to the expectation that they would make greater use of GP services, especially around the transition to care. Several explanations may be involved. Taking on a caring role may enhance carers' coping strategies over time, reducing the need or desire to consult a GP. Those carers who require frequent or regular contact with a GP may withdraw from caregiving although there is no evidence that this was the case here. Some carers may be referred by their GP, or seek practical help and emotional



support from family and social networks. As caregiving extends, carers are likely to encounter a range of health and social care practitioners who provide services for the cared-for person and indirectly support their caring role; they may also draw on specialist services such as carers' centres and carer support groups and possibly experience fewer health problems of their own as a result. Some carers also face difficulties that limit or discourage access to GP services: these are discussed in the next section.

### **Barriers to carers' access to health care services**

Analysis of the 20 studies looking at access to health care for carers found that carers face five main barriers to accessing health care:

- Barriers related to professional responses.
- Barriers related to service organisation and delivery.
- Barriers related to language or culturally held beliefs and practices.
- Barriers related to carer or care recipient characteristics.
- Barriers related to lack of information and knowledge.

#### *Barriers related to professional responses*

The review identified various ways in which professional responses or behaviours induced or perpetuated barriers to health care for carers. There is

strong evidence that health professionals often failed to recognise the caring role, did not recognise young carers, prioritised the care recipient at the expense of the carer, and were not aware of the needs and issues involved in caregiving (Aldridge and Becker, 1993; Henwood, 1998; Twigg and Atkin, 1994; Frank, 1995; Leeds Family Health, 1996; Katbamna et al., 1998a; Beaver et al., 2000). Some older carers reported that GPs were biased towards patients from a young age group, and did not understand older people or the particular problems they faced as carers – an issue also raised in the consultation (Arksey et al., 2000; Walters et al., 2001).

The professionals' approach can be understood in terms of their conceptualisation of carers. Twigg and Atkin (1994) found that GPs viewed carers in terms of their relationship with the care recipient. In so far as GPs did perceive carers as such, it was often with an instrumental emphasis, regarding them as a resource and not as a patient with their own health and social care needs. In a Canadian study of community nurses, concern for the well-being of the carer was generally minimal with the exception of those carers – especially women – who were elderly or had chronic health conditions themselves and seen as people in need of care in their own right (Ward-Griffin and McKeever, 2000).

Professional behaviour restricts carers' accessibility to health care in other ways. There is evidence that GPs and members of the primary care team often become involved only when asked – usually when a problem has arisen (Leeds Family Health, 1996; Simon and Kendrick, 2001). Contributors to the consultation felt that the reactive culture of health services works against a preventive approach that can protect the health of carers, and delay or prevent crises such as emergency admissions to hospital.

Uncertainty about professional roles and responsibilities emerged as another barrier to working effectively with carers. A postal survey of GPs and district nurses showed that many respondents from both study groups regard supporting carers as the task of someone other than themselves - often, each other (Simon and Kendrick, 2001).

#### *Barriers related to service organisation and delivery*

The literature indicated that not identifying carers and having systems in place to 'tag' carers' records – a government priority – is a major barrier inhibiting their access to primary care (Simon and Kendrick, 2001). Contributors to the consultation confirmed that many services do not take active steps to identify and record carers, especially those not living with the cared-for person, or those

registered with a different practice. Awareness training is positively associated with identifying carers and routine follow up, yet training in carers' health issues is not widespread (Simon and Kendrick, 2001),

Inflexible appointment systems that do not fit well with caring (and other responsibilities) often hamper carers' access to health services (Leeds Family Health, 1996; Katbamna et al., 1998a). Lengthy or unknown waiting times make it difficult to plan appointments around the pressing need to fulfil routine care tasks (Henwood, 1998; Katbamna et al., 1998a; Beaver et al., 2000; Newfield et al., 2002). Additional problems include reception staff acting as 'gate-keepers' and blocking access to the doctor. Surgeries with too many stairs (Katbamna et al., 1998a) and car parking which is hard to locate or some distance from the surgery (Newfield et al., 2002), exacerbate access problems for carers.

Contributors to the consultation felt that the cost of certain health services are a potential deterrent to some carers. In many areas, some types of health care (for example, flu vaccinations) have to be paid for by carers, even though they are offered free to other vulnerable patient groups, health staff and paid carers. Contributors thought that complementary therapies may also benefit carers (and there is supporting evidence; for example McDonald, 1998; Lazarus, 1998;

John, 2000), but again the cost is seen as deterring carers from using such services.

*Barriers related to language or culturally held beliefs and practices*

Both the review and the consultation showed that language can inhibit access to health care for carers whose first or preferred language is not English (Katbamna et al., 1998a; Gerrish, 2001; Neufield et al., 2002). One solution is to make more use of interpreting services, yet Gerrish (2001) found that district nurses rarely use these services. Having to book interpreters in advance is not conducive to the nature of district nursing, which often needs a more immediate response. Some district nurses lack confidence in the detail and accuracy of translations, and few have received training in working with professional interpreters.

Minority ethnic carers report experiencing racial prejudice and stereotyping, and some feel that services are provided or refused on the basis of ethnicity rather than need (Katbamna et al., 1998a). They believe that professionals lack sufficient knowledge about the cultural and religious aspects of their lives and do not appreciate, for example, how some groups value access to a same sex doctor – seen as particularly important for women.

Recent immigrant and refugee carers face wide-ranging access problems (such as language difficulties, racism, discrimination, lack of knowledge, uncertain status, limited means and social support) given their unfamiliarity with the types of services available (Neufield et al., 2002).

*Barriers related to carer or care recipient characteristics*

The review showed that carers' own help-seeking behaviours and approach to caregiving can potentially restrict access to health care. For instance, one study suggested that carers who are 'engulfed' by their caring activities are less likely to ask for, or accept, help for themselves (Twigg and Atkin, 1994). Caring for a spouse with limitations in daily living activities predicts poor preventive health behaviours by the carer in respect of inadequate rest, not finding time to exercise, not having time to rest when sick, and forgetting to take medications (Burton et al., 1997). It is suggested that feelings involved in caring – fear, pain, loss, guilt, resignation, duty – might interfere with carers' ability or inclination to seek help (Sisk, 2000; Walters et al., 2001).

Many young carers are not willing or confident enough to approach a GP about their own needs; those that do might not be assertive enough (Aldridge and Becker, 1993). On the other hand, young carers do make use of confidential

'drop in' services run by school nurses, yet their concerns about confidentiality and not wanting things to go further restrict the amount of practical help that nurses can offer (Aldridge and Becker, 1993; McClure, 2001).

*Barriers related to lack of information and knowledge*

Information is essential for carers of all ages and they can suffer stress and ill health because of uncertainty about how best to help the care recipient (DH, 1999). Nonetheless, the review found that GPs and other members of the primary care team, and hospital staff, often do not give carers information about the range of services available and how to access them (Ward and Cavanagh, 1997; Henwood, 1998; Katbamna et al., 1998a; Walters et al., 2001; Newfield et al., 2002). Other information gaps relate to welfare benefits, the practical aspects of caring such as correct lifting, and medical information about the care recipient. Obtaining information about medication and care is a particular struggle for carers who do not have the same GP as the care recipient (Arksey et al., 2000), for young carers (Aldridge and Becker, 1993; Bibby and Becker, 2000), and for those supporting someone with mental health problems (Twigg and Atkin, 1994).

In light of the evidence detailed above, what can be done to improve carers' access to health care? The following section focuses on interventions designed to improve accessibility.

### **Interventions to overcome barriers to primary care**

Six evaluation studies included in the review examined primary care support initiatives located in the London area (Naish and Benaim, 1995; Morris, 2002), Paignton and Brixham (Stevens, 1999), Newhaven (Lloyd, 1996), Burwash (Tarry, 1998) and Cornwall (Morris, 2000). Summary details are given in Appendix 2 (see also Arksey, 2003). Primary care support initiatives first emerged in the early 1990s within the context of the new community care regulations (Unell, 1996), and are designed to promote and protect the health of carers. Generally, initiatives are small-scale, developmental and funded for one or two years. Funding bodies vary; for instance, financial support for the six evaluation projects came from the King's Fund Centre, family health service authorities, health authorities, a health action zone and the National Lottery. Staffing often comprises one carer support worker, working on a part-time basis or in different practices. There is no single blueprint for how primary care support initiatives operate. Some concentrate on direct work with carers, while others emphasise educational and development work so that the effects of the



project will be felt long after it has ceased to operate. The more ambitious projects try to engage in strategic work with primary care groups/trusts. The sustainability of new systems and procedures is of paramount importance if development work initiated by project workers over a fixed time scale is to continue when funding runs out. An evaluation conducted 18 months after 'practice carers' contacts' had replaced the original carer support workers taking part in a pilot scheme in Cornwall suggests mixed success in terms of lasting impact (Morris, 2000). The provision of information to carers was the only task still undertaken in all four participating practices. All the systems required to maintain a register of carers, to identify and record patients who are carers, and to maintain a recall system for carers were in place in one practice only.

Regardless of the model implemented, evidence from the evaluation studies suggests that primary care support initiatives can address the full range of barriers to health care that carers confront.

#### *Barriers related to professional responses*

Primary care support initiatives try to directly influence professional ways of behaving towards, and thinking about, carers. For instance, a key priority for the carer support workers in all the initiatives reviewed is training and raising

awareness about carers' issues with members of the primary care team, and there is evidence that their efforts are successful (Tarry, 1998; Stevens, 1999; Morris, 2002). Staff who have personal experience of caring or a real understanding of the carers' situations are more likely to implement carer-focused systems within their surgeries (Morris, 2002).

#### *Barriers related to service organisation and delivery*

All six primary care support initiatives helped surgeries to implement systems to identify carers and tag records. Identification was generally acknowledged to be difficult. Some surgeries taking part in the Hackney and Brixham GP Carers Project, and also the Newhaven Carers Project, routinely ask whether people have a caring role at new patient registrations, over 75s and 'well person' screenings, and other standard health checks such as asthma clinics (Naish and Benaim, 1995; Lloyd, 1996). Asking about caring responsibilities on repeat prescription forms can be a useful mechanism to identify carers who are not registered at the same surgery as the care recipient (Naish and Benaim, 1995; Morris, 2002). One GP practice in the Brent Primary Care Project began work with a local school nurse and a carer support worker to make contact with young carers in local schools (Morris, 2002).

One project piloted a special 'carer health check appointment' for carers of elderly mentally ill people, where carers' health, caring situation and concerns about the person they are caring for could be addressed (Naish and Benaim, 1995).

Contributors to the consultation stressed that in successful primary care support initiatives, referral protocols are kept as simple as possible and carers are generally able to self-refer. This might well imply the need for lower entry levels so that carers can access preventive rather than reactive support, for example by the proactive offer of well-being checks or flu vaccinations.

*Barriers related to language or culturally held beliefs and practices*

The evaluation report documenting the Brent Primary Care Project was the only one to make any sort of reference to the importance of actively attempting to reach carers from minority ethnic groups, especially those who do not speak or read English as their first language (Morris, 2002). Advertising through community resources, such as places of worship, post offices, local shops and papers, was suggested. The report also recommended establishing local support groups which utilised community resources and which had an awareness of cultural diversity.

### *Barriers related to carer or care recipient characteristics*

The evaluation studies showed how primary care support initiatives attempted to address the way in which many carers accepted their situation and did not expect anything from health care professionals apart from appointments on request, obtaining prescriptions, or referral to specialist medical clinics (Morris, 2002). For instance, one of the good practice points for general practice staff reported in the Brent Primary Care Project evaluation states: 'Support carers to recognise and value their own role and the need to care for themselves' (Morris, 2002: p. 30).

The Hackney and Newham GP-Carers Project produced a carers' guide to good practice, which aimed to give carers some ideas about how GPs and surgery staff could be a source of support (Naish and Benaim, 1995). One section of the guide, called 'Getting the ear of your GP', attempts to overcome carers' reluctance to seek professional help by saying that GPs dislike being faced with crisis situations, and recommends that carers arrange a consultation with them sooner rather than later. It also points out that those carers who might feel uncomfortable about approaching their GP directly should consider who else within the practice could help them.

### *Barriers related to lack of information and knowledge*

The provision of information is a key function of all the primary care support initiatives included in the review. Information packs and directories of local and national carer support facilities were developed by carer support workers during the lifetime of some of the initiatives (Naish and Benaim, 1995; Lloyd, 1996; Morris, 2002). Ideally, these are kept up to date by the carer support worker or a nominated member of the practice staff. Carer support workers also signpost carers to relevant agencies in both the statutory and voluntary sectors. They provide advocacy and benefit advice, and often help carers to complete claim forms for attendance allowance in respect of the person supported (Lloyd, 1996; Tarry, 1998; Morris, 2000; Morris, 2002).

It is difficult to identify and quantify to what extent and in what ways primary care support initiatives overcome access barriers. However, there is evidence that awareness training is associated with identifying carers and routine follow-up (Simon and Kendrick, 2001), functions that limit access to health care for carers if not fulfilled. Evidence from the six evaluations also indicates that initiatives are potentially beneficial for certain groups of carers: carers with a visible presence in the GP surgery, older carers, 'hard-to-reach' carers, and carers in need of advocacy.

## **Discussion**

This paper has investigated the difference that caregiving makes to carers' access to and use of GP and primary care services. The first part shows that carers' use of GP services varies according to the individuals' location in the caregiving trajectory. Surprisingly, women who carry heavy caring responsibilities for someone in their own household seem to have relatively less contact with GPs than expected. The second part identifies five different types of barriers that inhibit carers' access to primary care services, which might help explain lower consultation rates.

That carers face particular barriers because of their caring role would support the case for carer-specific interventions to improve access and reduce potential inequalities in unmet needs for primary care services. The approach of the Modernisation Agency, one of the key bodies charged with helping NHS trusts improve access, is to improve the whole system to the benefit of all patient groups rather than introducing initiatives for specific groups such as carers. Clearly, universal or generic measures to improve access, such as Waiting, Booking and Choice, Advanced Access, Walk-in Centres and NHS Direct, are likely to benefit carers in general, although no evaluations focusing specifically on carers' use of these services were found. Moreover, generic initiatives

primarily address barriers associated with service organisation and delivery (e.g. the convenience of appointment times) and are unlikely to have any impact on the other barriers that carers face. Ideally, the aim is to create a national service framework or infrastructure within which to develop appropriate, targeted responses to those with particular needs (Titmuss, 1968). As in other policy arenas, equality of access and of outcome may require positive and sensitive discrimination to avoid socially divisive services.

The findings presented here confirm that GP surgeries can provide a productive setting in which to identify adult carers, offer advice and information, and refer carers for a social services assessment of needs. Additionally, specific interventions to enable carers to maintain their own health and receive training in basic nursing tasks might be appropriately located in primary care settings. The challenge is to develop effective methods for identifying carers that are acceptable to GPs (Keeley and Clarke, 2003). Carers who are not in regular contact with a GP may require different approaches, for example involving community pharmacists in identifying hidden or hard-to-reach carers (Princess Royal Trust for Carers, 2003).

The evidence suggests that GPs and other members of the primary care team respond to carers' needs only when asked. This reactive stance draws attention to a mismatch between the proactive approach envisaged for primary care services by the government and the role that health professionals often see for themselves. Part of the problem may be that it is difficult to find good evidence of the effectiveness of measures to reduce inequalities in access to, and unmet needs for, GP and primary care services. Primary care support initiatives, for example, are promoted as beneficial for carers, but there is a paucity of evidence regarding their effectiveness in general and cost-effectiveness in particular. Without this sort of evidence, it is hard to convince doctors of the benefits of actively supporting carers.

There is a need therefore to evaluate carer-specific measures designed to improve accessibility, including the various methods for identifying carers and supporting them in their caring role. Monitoring the impact of an incentive in the new GP contract to introduce a protocol for identifying carers might be one route for undertaking such work. Meanwhile, evidence on what carers find helpful is accumulating, and clear entry points for policies and interventions can be identified. Increased awareness of carer issues among policy makers,



primary care trusts and professionals is motivating efforts to implement and evaluate initiatives.

A range of practical material is available to help health professionals examine and improve their support for carers. These documents include: good practice guides for GP surgeries and primary care support initiatives (Warner, 1999; PRTC, 2003; Keeley and Clarke, 2003); guidelines for primary care teams working with South Asian carers (Katbamna et al., 1998b); a checklist of quality standards for local carer services, including support for carers to maintain their own health and well-being (Blunden, 2002); a model to identify and support carers in general practice (Spinney Carers Project, 2001); and a planning tool to ensure services in health care settings are responsive to carers' needs (Newcastle Carers Project, 2002). To encourage take up, these approaches should be evaluated for their transferability, sustainability, effectiveness and cost.

Our research suggests that further investigation of carers' help-seeking for health care, and the factors involved, is warranted. Understanding how caregiving influences the ways in which people manage their own health, and seek help from GPs and members of the primary care team, has important

implications for implementing the government's strategy of enabling carers to maintain their own health and well-being, and developing the role of health professionals who might help them. Such an understanding would underpin the effectiveness of advice and support to carers, and the prospects for developing a genuine partnership between them and professional carers.

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## Appendix 1

### Summary of Core studies (n=7)

The 'core' studies are those studies included in the review that contain the best evidence available. They comprise good quality pieces of research and contain data that have a direct bearing on issues relating to access to health care for carers.

Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Setting
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 responses; Service organisation and delivery.	UK
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 responses; Service organisation and delivery; Lack of information and knowledge.	UK
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.	Carers (n=121).	Carer or care recipient characteristics.	USA

Author(s)	Study aims	Carer Group	Research design and method of data collection	Sample	Barriers identified	Setting
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 responses; Service organisation and delivery.	UK
Burton et al. (1997)	To seek knowledge about preventive health practices of carers.	Spouse	Quantative methods: structured interviews.	High-level carers (n=212). Moderate-level carers (n=222). Control group (n=385).	Carer or care recipient characteristics.	USA
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 responses.	Canada
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 responses; Carer or care recipient characteristics; Lack of information and knowledge.	UK

### Summary of Intermediate studies (n=7)

The 'intermediate' studies focus on the central issue of access to health care to a lesser extent or their quality is somewhat less robust.

Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
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 responses.	UK
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; document analysis; outcome measures.	Carers (n=51). Social services managers (n=5). Social services practitioners (n=16).	Professional responses; Lack of information and knowledge.	UK



Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
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; Lack of information and knowledge.	UK
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 organisation and delivery; Carer or care recipient characteristics.	USA
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 responses; Carer or care recipient characteristics; Lack of information and knowledge.	UK
Frank (1995)	To investigate the needs of young carers.	Young carers	Qualitative methods: interviews with young carers.	Young carers (n=16).	Professional responses.	UK

Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
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 responses; Lack of information and knowledge.	UK

### Summary of Supplementary studies (n=6)

'Supplementary' 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.

Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
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. Semi-structured interviews.	Registered patients aged 75 years and over (n=55). Carers (n=15)	Professional responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	UK
Ward and Cavanagh (1997)	To identify carers' health and social care needs.	Generic	Qualitative methods: focus group discussions.	Carers (n=103).	Professional responses; Service organisation and delivery; Lack of information and knowledge.	UK

Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
Katbamna et al. (1998a)	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 responses; Service organisation and delivery; Language or culturally held beliefs and practices; Lack of information and knowledge.	UK
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 organisation and delivery; Lack of information and knowledge.	UK
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 culturally held beliefs and practices.	UK

Author(s)	Study aims	Carer group	Research design and method of data collection	Sample	Barriers identified	Setting
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 organisation and delivery; Language or culturally held beliefs and practices; Carer or care recipient characteristics; Lack of information and knowledge.	Canada

## Appendix 2: Summary of Evaluations of Primary care support initiatives (n=6)

Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/evaluation design	Setting
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 responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	Mixed methods: interviews and questionnaires.	UK
Lloyd (1996)	Newhaven Carers Project. To promote and protect the health of carers.	Generic	Professional responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	Qualitative methods: interviews and attendance at meetings.	UK
Tarry (1998)	Carers Primary Care Project at Fairfield Surgery, Burwash. To identify and assist carers.	Rural	Professional responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	Qualitative methods: interviews.	UK
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 responses; Service organisation and delivery; Lack of information and knowledge.	Mixed methods: interviews, questionnaires, contract documents, correspondence, minutes of meetings, interim and final reports.	UK

Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/evaluation design	Setting
Morris (2000)	Cornwall Carer Support Workers Service. To improve support for carers offered by primary health care practitioners.	Generic	Professional responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	Quantitative methods: post-intervention questionnaire survey.	UK
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 responses; Service organisation and delivery; Carer or care recipient characteristics; Lack of information and knowledge.	Mixed methods: interviews and training evaluation forms.	UK

Figure 1 Women co-resident carers providing 20+ hours care per week:  
number of GP consultations per year before (c0) and during care episode (c1 to  
c5)

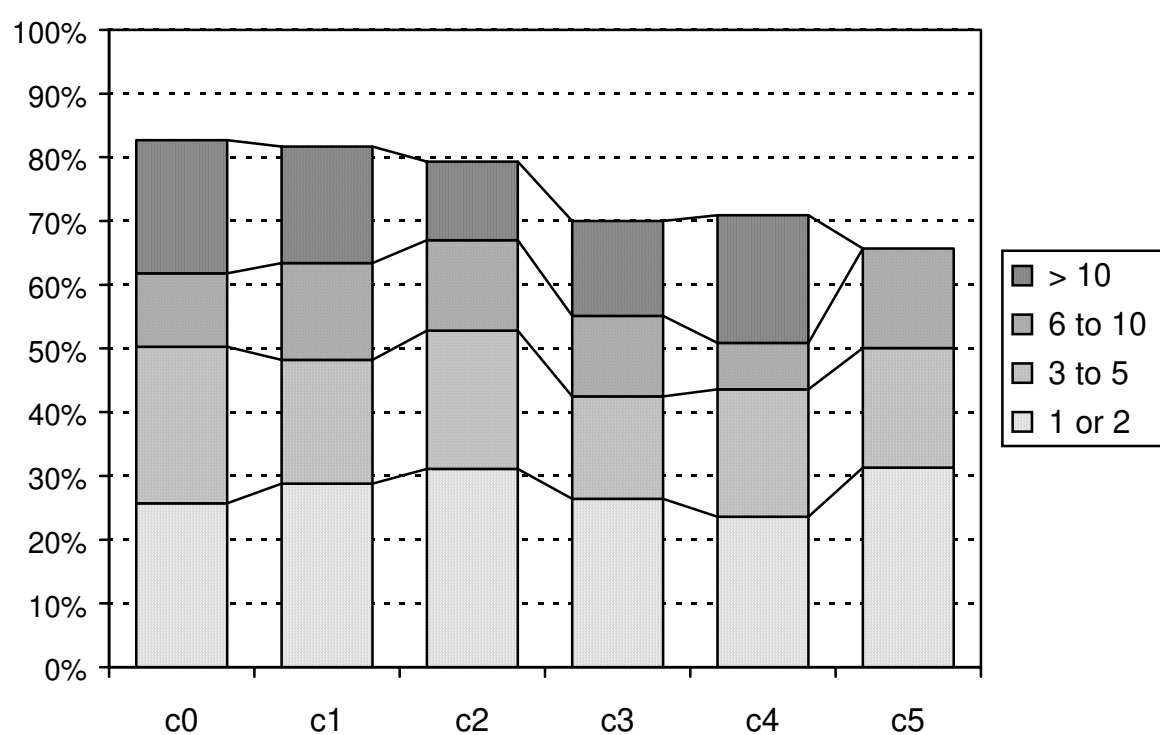




Figure 2 Men co-resident carers providing 20+ hours care per week: number of GP consultations per year before (c0) and during care episode (c1 to c5)

