Informal carers and the primary care team

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SUMMARY

The number of carers in the community is rising, and the importance of general practice in providing support for them has been highlighted. Caring for a disabled friend or relative has been shown to be harmful to the health of the caregiver and changes in social and family structure have led carers to become isolated and more reliant on the formal support services. However, many carers feel that GPs do not understand their needs, and in turn many GPs and nurses feel that they lack the relevant resources and training to take a more proactive role. The shift from hospital to community-based care and the blurring of social roles of responsibility puts additional pressure on the carers and community services. However, general practice is in the best position to help and there are many things that can be done by primary care teams, such as providing information about available support, benefits and local services, which would be appreciated by informal carers.

Keywords: *caregiver; community care; primary care; support services.*

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Introduction

CARE in the community is a government priority [1-4] and often elderly or disabled individuals are cared for at home, looked after by relatives and friends, with support from the primary care team. There are six million carers in the UK (one adult in seven) and it is likely that this figure will rise in future.[5]

Caring for a disabled friend or relative has been shown to be harmful to the health of the caregiver. In one survey, 52% had been treated for stress-related illnesses since the onset of caring and 51% reported physical injury as a result of caring.[6] Studies of carers of stroke patients have revealed that 40% report poor psychological health[7-9] and similar findings have been seen with carers of elderly patients.[10] Social effects, such as reduction in social contact and financial loss, have also been consistently recorded.[11,12] All-cause mortality may be increased by up to 60%.[13]

The beneficial effects of caring are less well documented but also exist.[14-16] Some carers find fulfilment in the role of carer. Others would rather look after a friend or relative than leave them to the care of formal services. Success in that goal provides satisfaction.

There have always been informal carers but the issue of formal care for carers has only come into prominence over the past 20 years. Change in social structure, the loss of the extended family[17] and improvements in transport and communications, have led to a loss of local community and relatives living too far away to be of any practical assistance. As a result, informal carers have become isolated and more reliant on the formal support services. Secondly, our population is ageing[18] and more people survive illnesses that were previously fatal. There are more disabled people in the community and thus more carers. As carers are frequently spouses,[19] the carers are becoming older and frailer too and need more help from formal support services.

Carers and primary care teams

Most community care is provided by friends, family, and neighbours. On average, 88% of informal carers have seen a general practitioner (GP) and 51% a district nurse[6] within the past year. When asked who has the most power to improve their life, 72% of carers rank their GP top of the list.[6]

The Griffiths Report[20] highlighted the importance of general practice in providing this support. In the 1999 National Strategy for Carers[2] it was formally recognised that, for many carers, the most important initial point of contact is with their GP or another member of the primary care team. At government level it is clearly regarded that GPs have a key role to play in supporting carers and influencing service providers in their local community.

However, problems of interaction between GP and carer have been identified as a reason for delay in access to support services and a source of stress to carers.[21] National surveys of informal carers by carers' representative organisations

have shown that only half have any contact with any member of the primary care team other than the GP.[6] However, 71% feel that their GP does not understand their needs[22] and 40% feel that their GP could have done more for them.[6]

Research in this area with GPs has concluded that much of this is down to the biomedical stance of the GP and the lack of training GPs have received about social issues.[23] GPs are left either to ignore or marginalise carers and their problems or to draw on personal experience and common sense to deal with the problems that carers might face.[23]

The definition of a carer

Another problem for the GP and primary care team lies with the definition of an informal carer. Parker[24] defines informal carers as 'persons providing care for a disabled relative or friend at home, and who are unpaid'. This definition encompasses a huge range of carers and highlights the heterogeneity of the group. Care provided can range from moral support from afar, to practical hands-on care day and night. Those cared for range from patients with physical disability to patients with psychiatric problems. Carers range from children to elderly spouses. Stresses and rewards of caring are different depending on the problems the patient has,[25,26] the amount of input the caregiver gives,[25,26] the length of time that the caregiver has been providing that care,[27] the age,[26] sex,[28-30] and social background[31] of the carer, and the relationship of the caregiver to the patient.[27] Moreover, many carers do not see themselves as such — caregiving is just an extension of the role they always had. When does a carer become a carer?

How do GPs and other members of the primary care team view their roles?

A recent survey of GPs and district nurses carried out from our unit showed that most see themselves only in a reactive role — responding to carers' problems as and when they occur. Both groups consider they have insufficient time, resources, and training to fulfil a more proactive role and that other groups were better suited to its demands.[32-33] Despite changes in health and social care provision,[2,3,34] the emphasis on care of informal carers, and guideline provision,[35] this view has remained remarkably static over the past 10 years.[23,36]

There is a major issue of shifting roles. Inpatient care is expensive and there is financial pressure for patients to be returned to the community within the shortest possible time.[37] Evidence in some conditions supports early discharge into the community as beneficial to the patient.[38,39] Consequently, community services and informal carers take on the burden of care earlier and at a point where more input is required.[40] Similarly, care in the home is both a cheaper and better option for most patients than long-term residential care.[41] More disabled people are being returned to the community, putting additional pressure on the carers and community services.

As a result of the shift from hospital to community-based care and increasing patient expectations, GPs and other members of the primary care team feel increasingly overburdened with work. In an attempt to limit their roles, they are perhaps becoming more preoccupied with role definition.[42,43] A GP is no longer the doctor in the community who will turn his hand to anything. Carers have no formal medical diagnosis and do not suffer from a specific medical condition. They are seen as having social, rather than medical, problems[23,33] and thus being on the periphery of the GP's role — an area where general practice could absolve its responsibility.

On the other hand, general practice is in a position to help carers as never before. The advent of Primary Care Groups and Trusts gives GPs and social services new avenues of cooperation to support carers, and there are examples of successful schemes for carer support as a result.[44] New technology can ensure effective inter-agency communications and should streamline services provided to carers. Likewise, widespread telephone access and increasing Internet access should ease the support of carers tied to the home.[45-47]

Proactive care

General practice has seen a shift over the past 20 to 30 years from reactive to proactive care. Prevention of diseases, such as coronary heart disease, stroke and cancer, has become as important as treating patients with disease.[48] Likewise, early identification and treatment of diseases such as diabetes to prevent complications has become the norm.[48] We know informal carers develop health problems that may be avoidable. We know informal carers feel that they would benefit from acknowledgement of what they do, practical support, and recognition of the physical, social, emotional, and financial costs of caring.[6,36,49] When appropriate they would like help either to discontinue their caring role or set boundaries to their caring.[23,36] There is potential for prevention; however, GPs are justified in being reluctant to commit time and resources to this area without information — which, at present, is lacking — about which interventions to use and proof that they are beneficial.[49,50]

Evidence of effectiveness

As resources are not infinite, it is necessary to find ways in which the primary care team can target limited resources to achieve maximum satisfaction and benefit with the resources available. Work done to date about the role of GPs and primary care teams in the care of informal carers consists of three main areas of research.

Qualitative studies using mixed groups of carers have identified that carers want primary care team members to recognised them as carers; to be given information about benefits, available services, and the medical condition of the person they care for; and to be referred to appropriate services with an explanation of why the referral is being made. Lastly, they would like primary care team members to be tolerant and not 'fob them off' and to hear (and interpret) what they say.[36,49]

Quantitative surveys of carers' opinions suggest that carers would like access to services that they do not currently receive;[51] in one survey, 57% of those not receiving district nursing services felt that they could benefit from them.[6] This reflects the assumption in the literature that formal support from the primary care team is a mediator of the stress

process and improves outcome in terms of health of the carer — but is this in fact the case? Opinion is almost equally divided between there being[52] or not being[51,53] a link between the amount of formal care provided and informal carers' health. There is also weak evidence for a link between carer satisfaction with services provided and the health of the carer.[54,55]

Trials of specific interventions for use within primary care are numerous and very varied, ranging from multimedia information provision[56] through carer education,[57-59] to specialist supporters for patients and carers.[60-63] Unfortunately, owing to the variety of definitions of carer used and outcome measures employed, it is difficult for direct comparison to be made between studies.[50] Moreover, many studies are underpowered[64] and tend to lack non-carer comparison groups,[64,65] preventing any conclusions from being drawn.

What can primary care teams do now?

Informal carers are vital, both to the care of our patients in the community and the economy of our country, and we are in the frontline of their support. Although questions remain about effective interventions, Box 1 lists the many things that can be done now which we know would be appreciated by informal carers — most of which are neither time consuming nor expensive in terms of resources.

- Acknowledge carers, what they do, and the problems they have.
- Flag the notes of informal carers so that in any consultation you are aware of their circumstances.
- Treat carers as you would other team members and listen to their opinions.
- Include them in discussions about the person they care for.
- Give carers a choice about which tasks they are prepared to take upon themselves.
- Ask after the health and welfare of the carer as well as the patient.
- Provide information about the condition the person the carer is looking after suffers from.
- Provide information about being a carer and support available.
- Provide information about benefits available.
- Provide information about local services available for both the person being cared for and the carer.
- Be an advocate for the carer to ensure services and equipment appropriate to the circumstances are provided.
- Liaise with other services.
- Ensure staff are informed about the needs and problems of informal carers.
- Respond quickly and sympathetically to crisis situations.

Box 1: Measures general practitioners can take to improve the quality of life of informal carers.[23,35,36,49,66]

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