Who cares for the carers? The district nurse perspective

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Background. Community care of elderly and disabled people is increasing. Primary care teams are expected to provide support to the informal carers essential for its success.

Objective. To explore district nurse (DN) views about roles of the primary care team and what is needed for support of informal carers.

Method. A qualitative analysis of open-ended questions contained in a larger postal questionnaire.

Results. DNs viewed improved respite care, general support and information provision as priorities for supporting carers, and lack of resources and access as the main reasons why they could not be more active. They thought other team members might be better placed to take that role. GPs were seen as key members of the primary care team providing services, actively identifying carers and co-ordinating other services and team members.

Conclusion. DNs identified several areas of support for carers that could be improved: respite, information provision and general support services. They did not feel able to be pro-active in support of informal carers themselves and viewed the GP in that role as a central co-ordinator of care and services.

Keywords. Caregiver, community, health services.

Introduction

Support of informal carers is high on the Government agenda. There are six million informal carers in the UK who save £3.4 billion of public money annually. We know carers experience health problems and primary care teams are ideally placed to support them.

Previous work has shown that the majority of GPs are vaguely aware of carers' issues and embarrassed that they are unable to do more. Their response to carers is ad hoc and arbitrary. Nurse training is more holistic than medical training and encourages a wider view that extends to recognition of carers' needs. Further, district nurses (DNs) view carers as an important resource requiring support of nurses so that they can, in turn, support patients. In practice, they are limited by lack of contact with carers of patients not on their caseloads.

Since these studies were done, carers' issues have achieved more prominence. There have been major changes in Government policy to improve support for carers, and the role of primary care services in providing support has been emphasized. Boundaries of service provision have changed and guidelines about support of carers for use in primary care settings have been produced by carers' representative organizations. This study aims to explore DNs' views of their own role and how they see the role of the GP within the current framework.

Method

Open questions were included in a larger quantitative postal questionnaire of all 272 DNs identified via DN managers in East and West Sussex. Numbered questionnaires were used and reminders sent after 4 weeks to non-responders. The questionnaire was designed to establish what DNs currently do for informal carers and what they see their role to be. The results of the quantitative questions contained within the questionnaire are published separately.

An informal carer was defined as a ‘person providing care for a disabled relative or friend at home, and who is unpaid’.

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Open questions about care of informal carers in primary care were:

- What do you think your role should be?
- What services would you like to see for carers in your area?
- What do you see the role of the GP to be?

**Analysis**

There is no universally accepted method for analysing open-ended questions in postal questionnaires. Due to large volumes written by DNs, we applied qualitative principles of content analysis and charting to interpret the data. Responses to the open questions were transcribed onto a word processor. Initially, opinions raised in the transcripts were highlighted and then, using a cut-and-paste technique and Excel spreadsheet, extracted under headings or themes which are presented here as the results. Transcripts were analysed separately by three researchers (one is trained in qualitative research methods).

**Results**

Of 272 DNs identified, six were no longer practising. Of the remaining 266, 223 (84%) replied. The mean age of responders was 45 years (range 25–63). Most (196; 89%) were qualified with RGN or SRN; the remainder had SEN registration. Specialist DN training had been received by 196 of the DNs (88%) and 43 (19%) held degrees. The ratio of male to female DNs was 1:18 and responders included five single handers (team size varied from one to 13 members with a mean of 4.6) and 64 part timers (29%) ranging from eight to 34 hours (mean 22.2 hours) per week. Average weekly caseload was 34 patients, with a new patient:follow-up ratio of 1:5. These characteristics of DNs and their working patterns are similar to figures collected by the Audit Commission, suggesting that the sample was representative of DNs in England and Wales.

**General points**

Lack of time and resources were seen as significant barriers to improving care for informal carers. In practice, DNs found identification of carers difficult, especially if carers were not registered with the same practice or GP as the patients cared for, or if carers did not view themselves as carers. DNs recognized that carers were a diverse group, and the provision of tailored support would require a thorough assessment of an individual’s needs. This had implications for time and resources, specifically: training in assessing carers’ needs, developing protocols to guide health professionals and increases in manpower to implement effective support posed significant barriers.

“GPs are basically in the same situation as nurses—not enough time and resources to assist.” DN208

“We are often unaware of carers not on the district nurse caseload.” DN268

“Carers are not more alike as a group than women.” DN 9

“They (GPs) have an important role but in the present climate they have enough problems looking after their sick patients without becoming involved with well-people.” DN231

“We haven’t the staff or the time to seek out all carers to offer them help.” DN237

**Service provision**

Most DNs (92%) recorded their opinions about services they would like to see made available to carers. Three inter-related themes emerged into which all responses fitted. Many areas mentioned overlapped, and frequently DNs mentioned more than one service they would like to see provided (Fig. 1).

**Theme 1: respite.** The majority found respite services of all types inadequate. Quality and cost were seen to be a problem, as was the need for easier access to all types of care (including respite), especially in crisis situations. Particular pleas were made for more respite in the home (such as sitting services) and increased flexibility of respite. An important and paradoxical observation made by DNs was that respite often increased workload and stresses for carers. The most common reason given by DNs for this was the poor quality of care during respite.

“It is the emotional tie/long term responsibility that is so wearying. Respite is available but the patient often comes home in poor condition then more work/worry/guilt for carer.” DN 198

“More respite available—unfortunately this is finance led and many carers/patients are declining assistance when realising a payment is required.” DN174

“A service to take over from the carers to enable them to have some free time or a short holiday or to provide cover in an emergency to prevent admission.” DN69

“Regular respite care—a mixture of in the home and patient going into care so carer can go away if guilt feelings allow.” DN109

**Theme 2: information provision.** Many DNs expressed that this was inadequate. Some suggested telephone helplines whilst others advocated information booklets specific for a geographical area.

“That all carers have all the information to meet their needs and that this is readily available.” DN194
“More information. Carers helpline? Identified body for carers to approach, i.e. specific to carers, who are familiar with community care mechanics.” DN122

“A clearly advertised/publicised carers helpline (phone) and other routes, e.g. internet etc.” DN 82

“We do have an active carers group locally but not all carers will contact them. Useful to have information available at shops, post offices as well as surgeries to enable people to access it independently.” DN152

**Theme 3: general support.** More support groups (and good respite care to allow carers to attend) and general support services were suggested. General support services proposed included specialist carer support services (ranging from voluntary schemes such as ‘Crossroads’ to trained professional primary care or social services team members) and practical help with care (housework or gardening, aids and appliances, home care workers, financial assistance).

“More support groups and easier access to these groups. Written information specific to the area.” DN 145

“More group meetings for carers to exchange information they have been given—consequently freeing up DNs and GPs.” DN62

“Maybe the trust could employ a specialist who could counsel and offer advice/support to meet individuals needs. Also help with form-filling and understanding gobble-de-gook. Carers help line.” DN130

“Local counsellor to advise, support and provide information.” DN143

“I don’t think carers need medical help. I feel they need social services assistance, e.g. social workers.” DN107

“More input from social care, help around house and garden, particularly for elderly carers.” DN146

“In our area we have a carer services guide. In one area voluntary help is provided. This could be extended. A benefit bus should go into communities to explain benefits.” DN229

**Role definition**

**DNs’ views of their own role.** From a tick box question within the questionnaire, we knew that only one DN thought DNs did not have a role to play in care of carers. A reactive response (intervening only if requested) was favoured by the majority (147 DNs; 67%) though one in three of these DNs wanted to restrict their role to carers of patients on their current caseload. The remainder favoured pro-active care, i.e. actively seeking carers and offering help.

Half the DNs did not respond to the open question about their views on their role. Of those that did (105 DNs), 67 saw lack of time and resources as the major reason why a pro-active response would be impossible. Others (17 DNs) considered other team members (e.g. practice nurses, social services or health visitors) better placed to look after the needs of carers.

“There is not enough time to be pro-active—this would be a role for a health visitor for the elderly.” DN216
“We cannot be all things to all people. Not enough hours in a day.” DN204

“It would be a wonderful idea to seek out all carers but as DNs we simply do not have the time or personnel. This is not a cop out unfortunately it is a fact.” DN4

DNs’ views about the role of the GP. Comments were recorded from 93% (207) DNs, from which six inter-related themes were identified (Fig. 2).

(i) Identification. DNs thought GPs were in the frontline and needed to identify carers by highlighting notes (or computer records) or compiling registers—ideally in co-operation with other primary care team members.

“GPs can sometimes identify carers before services are brought into play and refer on for further support/advice.” DN35

“They should highlight to the PHCT those carers they are aware of and liaise with a designated PHCT member who has input with carers.” DN39

“To have register of carers, communicate with health visitors and district nurses to make them aware.” DN77

“To be pro-active in referring carers to appropriate services and keep a register in the surgery.” DN161

(ii) General support. The GP was seen as a key supporter of carers who should be aware of their special needs and problems and be prepared to give carers time and listen to their problems. The GP was also seen as someone who could provide advice to carers with attention to their individual context.

“To give the carer time on their own to express their fears and anxieties freely to the GP. Listen to their needs.” DN25

“Should have a good understanding of the pressures on carers. Should be approachable and prepared to listen.” DN67

(iii) Medical monitoring. DNs thought GPs should monitor medical needs of carers either opportunistically or (as carers tend to neglect their health and might find visiting the surgery difficult) by offering regular health checks.

“Counselling—recognizing early signs of depression due to the situation.” DN31

“Mainly being aware or perhaps offering a regular check up as carers often neglect themselves.” DN59

“Giving them recognition. Regular health checks. Making information and respite care available to those most in need and in need of a break.” DN243

(iv) Information provision. This was seen by DNs as a major role of the GP and they thought GPs should be aware of help and resources available to carers (including benefits) or be in a position to direct them to someone who is.

“Letting carers know what help is available and how to access that help.” DN18

“Identify carers and then empower them with knowledge/information—to enable them to know what’s on offer and make decisions.” DN23

(v) Co-ordination of services and referral. The GP was seen as a key figure in referral of carers to other agencies and liaison with other primary care team members (whether or not referral was required).

“GPs should always be available to offer help and advice to carers and know who to refer them to for help.” DN237

“They (GPs) are aware of carers on their patient lists and should refer to appropriate agencies.” DN2

“GPs are usually the frontline and are, as well as DNs, ideally placed to pick up and act on potential, possible or actual problems . . . they could act as the network centre.” DN51
“Having the knowledge to refer to appropriate services, being able to access the appropriate service (this is often needed today not a week or two down the road).” DN4

(vi) Advocacy. DNs viewed a role for GPs as advocates for carers by representing their needs to public bodies (e.g. social services, housing departments), directly providing services for carers (e.g. notice boards in waiting rooms) and influencing service provision (e.g. by representing carers’ needs on Primary Care Group committees).

“(GPs have a role) Referring carers on to appropriate services. Applying pressure within the PCG for more respite services.” DN61

“Identification, awareness of strain of caring, gatekeeper to services available, treatment of depression etc., advocate.” DN136

“GPs are quite powerful—and social services take notice of them—so be a voice and back up carers and nursing staff to get services.” DN221

There were very few views that fell outside this framework. Those that did (two DNs) took the stance that GPs had no place to play in the support of carers.

“Difficult to see a role for the GPs unless the carer is ill.” DN120

“Generally I don’t think GPs place carers’ needs high on their priority list.” DN117

Discussion

We are aware of theoretical dilemmas raised by using qualitative frameworks to analyse responses to open-ended questions on quantitative surveys. This paper was written in response to the volume and strength of opinion expressed by DNs in this survey. By employing qualitative analysis, we have been able to give voice to a range of opinions that preserves contextual information which was important to making sense of DNs’ responses. If we had quantified DNs’ responses, this would have been lost.

We acknowledge that our analysis is limited by lack of opportunity for theoretical sampling and an inability to ask responders to expand or clarify points or to extend the sample to obtain data that might contradict or modify the analysis. Lack of information about the views of non-respondents or respondents who chose not to answer particular questions and their reasons for omission is another criticism. However, the responses made by the DNs have important implications for the future organization and delivery of health services to informal carers. Additionally, we intend to use the findings from this study to inform the development of a formal qualitative study to test our findings.

All the researchers in this study were GPs. To counteract this, we manufactured critical distance from our own disciplinary biases. This involved reading literature from the nursing discipline, and talking about our findings with academic and practising DNs and other members of the primary care team. Additionally, our different research training (TK and CS quantitative research methods, SK qualitative research methods) and backgrounds (inner city, urban and rural practices) broadened the issues we identified.

The sample size was based on that required for the parallel quantitative survey which resulted in a large amount of qualitative information being produced. The high response rate and large, detailed amounts written in response to our open-ended questions (ranging from a few words to several sides of A4 paper) suggest that this is an important topic for DNs. We did analyse all the questionnaires and used incoming data to challenge or confirm previous findings. The large volume of opinion we collected emerged from a wide geographical area, which gives a level of representativeness and transferability to our findings.

Another possible limitation of this study was the restriction imposed by the definition of an ‘informal carer’ for which we chose to use—a ‘person providing care for a disabled relative or friend at home, and who is unpaid’. There is no universally agreed definition of an informal carer and some definitions are wider than others. For example, the National Strategy for Carers used a definition of someone providing care without payment for a relative or friend who is ‘sick, disabled, vulnerable or frail’, and the Princess Royal Trust for Carers defines the person being cared for as a relative, friend or child with ‘physical or learning disability; or who has a mental health problem, a long term illness or is frail’. Although we did not limit our survey to different subgroups of carers, our rather narrower definition of a carer may have indirectly done this and influenced the views DNs reported.

In discussing these results, we aim to acknowledge, seek to understand and challenge the views expressed by the DNs. DNs, through their work in the community with chronically disabled and terminally ill patients, come across carers frequently and are in a credible position to comment on facilities needed in the community and roles of different team members. We did not limit the survey to different subgroups of informal carers (e.g. those looking after patients with stroke) as preparatory work suggested that DN protocols did not differentiate between the types of patient the carer was attending (with the exception, on occasions, of informal carers of the terminally ill).

The validity of DNs’ views about needs of carers might be questioned, but in this study their views concur closely with those of carers themselves—namely improved respite, better information provision and increased general support. Despite having strong views on what
is needed, DNs did not view their role as pro-active in service provision, with the majority favouring a reactive response when carers or other agencies approached them. Reasons given were inadequate access to carers of patients not on their caseload, inadequate resources and a view that other services would be better placed to fulfil that role.

The DNs viewed the role of the GP as a central and pro-active one, identifying carers and co-ordinating services, providing medical and general support of carers, information, referral, liaison with other primary care team (PCT) members and advocacy. However, GPs still view their role as reactive and do not feel they have the training or resources to fulfil a pro-active role. They view it as the role of other team members to be pro-active.

Who then can support carers? Health visitors for the elderly and social workers were suggested as possible alternative candidates, but limitations of their roles were stressed. It is clear from Government policy statements, that support of carers is seen as a role for primary care services, but many of the respondents to both surveys commented that carers who were not ill were not part of their remit. It seems that the medical model still persists. Role Definition is important—do we as health professionals maintain health or manage disease? In many other areas of care, we are involved with the maintenance of health (e.g. immunization, hypertension management). Should carers be any different?

The counter-argument is that in other cases of preventative medicine, we know that our intervention prevents disease. There is good evidence that informal carers would like acknowledgement of what they do, practical support, recognition of the physical, social, financial and emotional costs of caring and help to set boundaries over the limits of their role. There is much less evidence that increased support from PCTs improves outcome in terms of physical, psychological or social health, and conflicting evidence about the best ways to deliver this care. In an age of evidence-based medicine, can we justify expending valuable time and resources without proof of efficacy?

What is health? If we use the World Health Organization definition of health as the physical, mental and social well-being of an individual, then carers fall within that definition of health as the physical, mental and social well-being of an individual, then carers fall within that. However, we as health professionals maintain health or manage disease? In many other areas of care, we are involved with the maintenance of health (e.g. immunization, hypertension management). Should carers be any different?

Both DNs and GPs have extensive general training, but both groups thought their training inadequate to deal with care of carers. This is a finding reflected by other literature. We are asking DNs and GPs to care for carers’ needs, yet only one in 10 GPs and one in three DNs report any training about the needs of carers. Is it surprising that health professionals do not feel equipped and are reluctant to take responsibility for the well-being of carers?

What needs to be added to GP and DN training to enable them to take on this role? The most common areas cited as problematic were information about benefits and local services. Computer packages are available providing ‘at-a-touch’ information about benefits, and the Citizen’s Advice Bureaux have a website with up to date information. It would be a simple matter to provide information booklets about local services as some practices already do. Are these factors really such a barrier to provision of care?

Time and resource limitations are also viewed as obstacles. Surveys of carers show that they want general support, information provision, co-ordination of services and access to services they require. As health professionals, we are in contact with carers on a regular basis anyway. They are our patients too, and services they want are not unique to carers. Most take negligible resources and little time to provide. Does provision of services carer’s needs represent such a major burden on our time or resources?

GP and DNs have a tradition of family practice. Informal carers are not new and primary care services traditionally have supported them. Why do neither GPs nor DNs view it as their role to care for carers now? Perhaps it is due to the political climate within health care. GPs are having their role simultaneously expanded and eroded and the nursing role is also changing. Both groups are protective of their position, and role definition is becoming ever more important.

Care for the six million carers in the UK is a huge problem, with major resource implications. With the advent of Primary Care Groups (and, more recently, Primary Care Trusts), we are in a position as never before to co-ordinate services at a local level for carers. However, if care is to become more pro-active, we need to show that adherence to practice guidelines is beneficial, define roles of PCT members, identify a chain of action and train team members to develop suitable skills and be confident in their ability to carry out their roles.

In conclusion, DNs see support of informal carers as an important issue and view insufficient provision of respite care and information as major deficiencies in the current support mechanism. They feel their role is limited by lack of training, contact, time and resources to a reactive one, responding to carers’ problems only when asked, and they see GPs as central co-ordinators of care.
References


