Informal carers — the role of general practitioners and district nurses

Chantal Simon and Tony Kendrick

SUMMARY
Six million informal carers provide support for aged and disabled people in the United Kingdom. Government policies suggest that primary care teams are the main support for carers. This postal survey of 300 general practitioners (GPs) and 272 district nurses (DNs) aimed to determine current practice and views on their role in supporting informal carers. In practice, GPs and DNs lack time, resources, and training to provide support, and see themselves in a reactive role only.

Keywords: support for carers; postal survey; current practice.

Introduction
Six million informal carers provide support for aged and disabled people in the UK.1 Government policy has emphasised the key role of primary care teams in supporting carers and influencing service providers in their local community.2 Each year, 90% of informal carers see a general practitioner (GP), and 50% see a district nurse (DN). Although carers perceive their GP as the person with most power to improve their life, GPs' performance seems to fall short of expectations.3

Previous studies about GPs' and DNs' self-perceived roles show health professionals have sympathy towards carers; however, time restraints, difficulty identifying carers, and lack of knowledge about carers’ issues, limit effectiveness.4,5 As well as health and social service reforms,2 and guidelines for support of carers have been produced by carers’ representative organisations.6 This study aimed to determine current practice and views of a representative population of GPs and DNs on their role in care of informal carers.

Method
GPs and DNs in Sussex were surveyed by postal questionnaire. Of 868 GPs identified, 300 were randomly selected using a computer generated list. All 272 DNs identified were surveyed. Four weeks after the first mailing, non-responders were sent a second questionnaire.

A carer was defined6 as an unpaid friend or relative of an aged, sick or disabled person at home in the community who attends to that person’s needs. Reactive care was defined as ‘being there for carers if help is requested’, and proactive as ‘actively seeking out carers and offering help’.

The questionnaire had four sections each containing questions with ‘yes’ or ‘no’ tick box answers: background information; training about carers; current practice, and views about carers’ problems and personal role. Space was given for comments where relevant. The χ² test was used to assess significance of association between pairs of variables.

Results
Of the doctors, 211 (71%) replied from 127 out of 249 practices identified. No significant differences were found between responders and non-responders, or responders and the Royal College of General Practitioners national practice data. Of the nurses, 223 (84%) replied. A wide range of working arrangements and caseloads were reported.

Recording carer status
Fewer than one in four GPs, and a third of DNs, routinely recorded whether someone was a carer. The difficulty of carer identification was stressed. GPs recording carer status...
were more likely to keep information for carers (94% versus 76%, \(P = 0.006\)) and follow them up (33% versus 4%, \(P < 0.001\)). Recording carers and follow-up by nurses were similarly linked (47% versus 27%, \(P = 0.004\)).

**Information**

Half the doctors and three-quarters of the nurses provided information routinely for carers (though more did so on occasion). Information was most frequently reported as being available in the waiting room (104 [49%] GPs and 115 [52%] DNs). Only 14 (7%) GPs and 94 (42%) DNs actively gave information to all carers identified, though more provided information on request.

**Training**

Only 10% GPs and 36% DNs had received any training about the health of carers (Table 1). Training varied from reading a magazine article to training on modular courses. Receipt of training was positively associated with recording of carer status (48% versus 21%, \(P = 0.008\) and 45% versus 31%, \(P = 0.04\) respectively) and follow-up (29% versus 9%, \(P = 0.007\) and 45% versus 27%, \(P = 0.01\) respectively).

**GP and DN role**

Views about role are given in Table 2. In the comments box, lack of time and resources was mentioned by 31 GPs (15%) and 70 DNs (32%) as the major reason why proactive care would be impossible. Other team members (e.g. social services or health visitors) were suggested as alternatives by 21 (10%) GPs and 15 (7%) DNs.

**Discussion**

As with all self-report questionnaires, this survey measured reported, and not actual practice. This is a potential limitation of the study. In general, such questionnaires seem to report rather better standards of practice than one would expect. Applying this to our data, the high reported availability of information may be an overestimate of the true availability of information in practice. The low reported incidence of recording carer status, training about carer issues, routine follow-up of carers, and provision of proactive care is thus all the more significant.

Both groups acknowledged that carers were prone to health problems as a result of their role. There is an assumption that GPs and DNs are best placed to support carers; however, several GPs and DNs found identification of informal carers difficult. Many carers do not see themselves as such and, even if questioned, would not declare that they were carers. Identification is especially difficult if the person being cared for is not registered with the same GP or practice as the carer, or is not on the district nurse caseload.

Another problem is role definition. Where does the role of a GP or DN end? Several responding GPs commented about role fatigue and many nurses and doctors regarded supporting carers as someone else's role (often each other's). The majority of both groups felt their role in support of informal carers was reactive; and that they should become involved with supporting carers only when asked, generally only if a problem had arisen. This implies a major gap between the proactive role envisaged for primary care services by the carers' organisations and government, and the role that GPs and DNs see for themselves.

### Table 1. Training and current practice among GPs and DNs.

<table>
<thead>
<tr>
<th></th>
<th>Number (%) GPs</th>
<th>Number (%) DNs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had received training about carers</td>
<td>21 (10)</td>
<td>81 (36)</td>
</tr>
<tr>
<td>Recorded carer status in notes</td>
<td>51 (24)</td>
<td>78 (35)</td>
</tr>
<tr>
<td>Routinely followed up carers</td>
<td>24 (11)</td>
<td>73 (33)*</td>
</tr>
<tr>
<td>Routinely provided information for carers</td>
<td>97 (46)</td>
<td>162 (73)</td>
</tr>
<tr>
<td>Written information available for carers within the practice</td>
<td>151 (72)</td>
<td>202 (91)</td>
</tr>
</tbody>
</table>

*30 DNs (41%) of those who routinely followed up carers only did so after bereavement.

### Table 2. GPs’ and DNs’ views on their role in the care of carers.

<table>
<thead>
<tr>
<th>GP and DN views of their roles</th>
<th>Proactive: actively seeking carers and offering help</th>
<th>Reactive: being there for carers if help is requested</th>
<th>No role for carers without specific medical problems</th>
<th>Missing response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number (%) GPs</td>
<td>52 (25)</td>
<td>136 (65)</td>
<td>12 (6)</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Number (%) DNs</td>
<td>47 (21)</td>
<td>147 (67)*</td>
<td>1 (&lt;0.5)</td>
<td>25 (11)</td>
</tr>
</tbody>
</table>

*47 DNs (32%) of those who favoured a reactive response) thought they should be reactive only to the needs of carers of patients on their current caseload. The remainder thought they should be reactive to the needs of any carer.
References


