A descriptive study of the self-perceived needs of carers for dependants with a range of long-term problems

Hester Ward and Julie Cavanagh

Abstract

Background This study aimed to identify qualitatively the need for health and social care of carers looking after dependants from different patient groups in a geographically defined area – Fife, Scotland. It was the first stage of a systematic process designed to assess and meet carers' needs.

Method Subjects for the study were unpaid (or 'informal') carers looking after dependants who were known to statutory or voluntary services. A series of 14 focus group discussions with carers of dependants from seven different patient groups took place. The main outcome measure was the qualitative descriptions of carers' self-reported health and social needs.

Results Needs 'common' to carers across all care groups were identified. These related to the need for: information (diagnostic, prognostic and where to obtain help), improved communication with professionals, relief from stress, respite care, training and practical support. Within each area of 'common' need, carers had specific needs, which related to the particular needs of their dependant. There were also needs that were identified by carers from one or more patient groups. Carers did not necessarily recognize themselves as carers at an early stage in their caring career. Therefore, their dependants' early medical contact with their general practitioner or hospital specialist was seen by carers as a crucial point at which their own needs for information and help could be recognized. Other opportunities for health professionals to help carers related to involving carers in case management, the provision of counselling and training carers to provide care themselves.

Conclusion Many of the needs described by carers were of a social nature. However, carers also described needs relating to the health services – health professionals need to be proactive in recognizing carers' health and information needs and are required to recognize carers' contribution to the welfare of their dependant. In Fife, a multi-faceted approach was used to meet these needs. The challenge for the health service is to find a way to do this at a national level.

Keywords: carer, needs assessment, focus group discussion

Introduction

It is estimated that six million people in the United Kingdom are carers, that is, they provide regular unpaid help and support to a relative or friend, who would otherwise not manage to live in their own home.1 By providing services and support for people affected by the problems of ageing, mental illness, mental handicap and physical and sensory disability, such carers have become the foundation on which care in the community is built. However, the burden of caring creates problems for carers themselves.

The Carers (Recognition and Services) Act 1995 requires that carers’ needs are addressed by local authorities as an integral process in care planning. Yet there has been little attempt to describe carers’ needs in a way that directs service planners and providers to understand the essential components of the care needed to meet carers’ needs. Furthermore, the input required from the National Health Service remains unclear.

Carers comprise a large and heterogeneous2 group, poorly characterized by routine statistics in the United Kingdom. Women are more commonly carers1,3 and spend more time performing caring tasks than men.1 The age of the carer typically depends on the relationship of the ‘most appropriate’ female relative to the dependant.3 Eighty per cent of carers look after a relation, and 40 per cent care for their parents.1 Older carers are more likely to have cared for a longer period before seeking help from statutory services compared with their younger counterparts.4

Research into the actual needs of carers has been relatively scarce and concentrates on professional interpretation of carers’ needs,5–11 rather than the needs carers describe themselves.12 Moreover, much of the research focuses on the elderly,3 and very few studies have investigated the needs of carers from more than one patient group.

Fife is located in Southeast Scotland with a population of approximately 350,000. In 1994 the needs of Fife carers were not being addressed in a systematic way. A Fife Carers’ Conference indicated that carers had many pressing and complex needs. To meet these needs appropriately and so to plan health and social services, a systematic framework had to
be developed. This consisted of the following:

1. A qualitative assessment of the needs of Fife carers.
2. A quantitative assessment of the needs identified in the qualitative study.
3. The identification of multi-agency solutions to meet these needs, which would inform the planning of health and social services.
4. The information obtained from the needs assessments would be essential in ensuring that individual carers’ needs assessments carried out by social services would be appropriately informed and focused.

This paper describes the first stage in this process — the qualitative assessment of self-reported health and social needs of Fife carers. In the discussion, we have concentrated on the implications of results for the National Health Service.

Subjects and methods
Systematic, non-probabilistic sampling of adult carers living in Fife was performed to recruit carers of dependants from the following patient groups: mental illness (excluding dementia), dementia, children with special needs, learning difficulty, physical disability, the elderly and frail, and long-term chronic illness.

Carers known to statutory services, voluntary organizations and to local carers’ groups were invited by letter and/or telephone to participate in one of a series of focus group discussions (FGDs). A maximum of ten carers of dependants from the same patient group were recruited to each focus group discussion. Transport costs and respite care were offered and group discussions were geographically dispersed around Fife. Each focus group discussion had a trained facilitator and scribe, was tape-recorded, and was transcribed by a trained transcriptionist.

Content of focus group discussions
Topic guides for focus group discussions were issued to facilitators and scribes at a briefing session. The main question to be discussed in the focus group discussions was: what were the specific needs of carers in the group and how could these be met? Carers were invited to discuss their needs as they were when they became a carer, as a carer now and in relation to gaining access to services, information and help. At the beginning of each discussion, carers’ verbal consent was sought for the recording and transcription of the discussion and for the publication of non-ascrbed data.

Analysis and quality control
Interpretative procedures were agreed before analysis. Each transcript was grouped and coded according to the topic guide. The transcripts and scribes’ notes were analysed by two independent researchers and the independent analyses for each focus group discussion were then compared and an interpretation was agreed by consensus. Transcripts were assessed independently to ensure quality control.

Results
In total, 103 carers took part in 14 focus group discussions (56 per cent of those invited) (Table 1). The time spent caring for a dependant varied within focus groups and between carers of different categories of patient (Table 2).

The needs of carers that were identified by all the patient groups in this study could be grouped under four headings — stress, information, professionals and respite care. The strength of feeling behind these needs was impressive from all the groups. Therefore, this paper concentrates on describing these key needs. Within each area of key need, carers had specific detailed needs, which related to their patient group. It is beyond the confines of this paper to describe these specific needs. In addition, outside the four key needs, there were needs identified by carers from one or more patient groups.

Recognition and the stress of caring
Quotes from FGDs describing the recognition of the caring role and the stress involved in caring
‘But I feel in need of support after all these years ... the doctor, visits, the practice sister visits, they all visit, but my husband is the focus...’
‘Some people don’t recognize that they are carers, I mean you build up to it gradually and then you realize that they’re talking about the kind of thing that you are doing.’
‘... it takes a lot of coming to terms with, to feel that other agencies than your own self are going to have to deal with what you feel is really your responsibility and your burden.’

The stress of caring
‘... at night I’m very tired, not physically tired, you’re mentally tired, you know, it’s stressful.’
‘I mean dying for somebody just to listen, or even dying for someone just to pick the phone up and say, “How are you?”’

Carers felt it was difficult to distinguish their needs from their dependants’ and had to be encouraged to describe their own needs. However, carers still felt that it was very important that their needs were recognized as distinct from their dependants’ needs.

There was no specific point in time when people identified themselves, or were identified by others, as carers; this caused difficulties for carers in realizing a need for help.

Stress was related to all the practical aspects and emotional aspects of caring, and was particularly highlighted by solitary carers. Conflicts of interests arose between the carer and the dependant, for example when the dependant assumed the carer could cope and did not want help.
Table 1 Attendance at focus group discussions (FGDs): numbers invited, numbers attending and number of FGDs undertaken; by patient group of dependant

<table>
<thead>
<tr>
<th>Patient group of dependant</th>
<th>No. of carers invited* to FGDs</th>
<th>No. (%) of invited* carers who attended FGDs</th>
<th>M:F ratio of attendees</th>
<th>No. of FGDs undertaken (numbers attending each FGD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with special needs</td>
<td>24</td>
<td>14 (58%)</td>
<td>1:13</td>
<td>2 (6, 8)</td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>31</td>
<td>19 (61%)</td>
<td>1:18</td>
<td>2 (8, 11)</td>
</tr>
<tr>
<td>Mental illness</td>
<td>24</td>
<td>14 (58%)</td>
<td>1:6</td>
<td>2 (8, 6)</td>
</tr>
<tr>
<td>Physical disability</td>
<td>47</td>
<td>22 (47%)</td>
<td>1:6</td>
<td>3 (8, 7, 7)</td>
</tr>
<tr>
<td>Dementia</td>
<td>28</td>
<td>18 (64%)</td>
<td>1:4</td>
<td>2 (9, 9)</td>
</tr>
<tr>
<td>Elderly and frail</td>
<td>20</td>
<td>12 (60%)</td>
<td>1:11</td>
<td>2 (7, 5)</td>
</tr>
<tr>
<td>Long-term chronic illness</td>
<td>11</td>
<td>4 (36%)</td>
<td>1:3</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Total</td>
<td>185</td>
<td>103 (56%)</td>
<td>1:7</td>
<td>14</td>
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*Carers who had returned application forms agreeing to participate in FGDs and who were subsequently given a range of dates and times to attend.

Appropriate information

Quotes from FGDs describing the need for appropriate information

'It's like being given car keys and a new car ... you know which is the left and right, but that is about all.'

'I think things are there if you know about them, but most of us don't really know about them. They don't come to you, you've got to go to them.'

'... we were getting what we weren't needing. We couldn't get what we were needing when we were needing it.'

When facing their new role, some carers knew help was potentially available, but did not know how to gain access to it, whereas others were unaware that they were entitled to help.

The provision of help was not systematic, but depended on the speed of onset of the dependant's illness, where the carer lived, who the carer was able to contact and the attitude of professionals. Often it depended on chance. With time, carers became more experienced in knowing what to ask for, and so obtaining help became easier. However, carers felt that this often improved help for the dependant, but not necessarily for themselves.

At the onset of their caring role, carers felt strongly that they wanted information to be provided by health professionals, that is, their dependant's general practitioner (GP) or hospital consultant, because they were usually the first professional contact the carer had. As they became more proficient, carers were willing to obtain help from more specific and diverse sources.

Carers needed information to be timely, actively offered rather than passively available, and specific, covering: the diagnosis and prognosis of their dependant’s illness; how to gain access to help and information regarding the caring role; and how to provide care and to obtain training in the caring role.

Professionals

Quotes from FGDs describing professionals

'... it is just the system as a whole, if you excuse me, stinks.

When you are trying to tie up everything together, each individual person in their field, or in what they can do for that moment, has been reasonably good.'

'... what I would like to see is the professionals really looking hard at this and saying we cannot do the job without the carers, just the same as we, the carers, know that we cannot do the job without the professionals. Then let the professionals show a bit of respect ...'

'... I have phoned the GP who has told me to phone the police, who told me to phone the GP and I have been going round in circles with someone who is being violent in the home ...'

Carers displayed mixed responses when talking of professionals. Whereas some individual professionals were liked and praised, most carers representing all patient groups felt that overall the professional response was insensitive, condescending and disrespectful. Professionals did not seem to acknowledge carers' expertise in understanding their dependant and in recognizing early symptoms of disease exacerbations.

The main issue was the focus of professional care. Whereas carers acknowledged the need for patient-centred care, focused

Table 2 Time spent in the caring role: self reported experience of caring by carers attending focus group discussions

<table>
<thead>
<tr>
<th>Patient group of dependant</th>
<th>Time spent in the caring role (years)</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>4.5</td>
<td>0.25</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Long-term chronic illness</td>
<td>8</td>
<td>3</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Physical disability</td>
<td>9.5</td>
<td>2</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Elderly and frail</td>
<td>12</td>
<td>4</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Children with special needs</td>
<td>14</td>
<td>2.5</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Mental illness</td>
<td>14.5</td>
<td>1</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>29</td>
<td>5</td>
<td>46</td>
<td></td>
</tr>
</tbody>
</table>
on their dependant, they saw no attempt by professionals to focus on the carers themselves.

Linked to this issue was the idea that professionals saw their role as delivering a discrete contribution to the dependant’s care, whereas the carer had to carry the continuing burden of responsibility for the dependant.

The perception prevailed that some health professionals lacked the specialist knowledge required to manage some dependants, and that this was particularly evident when professionals used to dealing with physical problems were confronted by mental disorder.

The professional response in a crisis posed particular problems. Faced with a violent dependant, carers felt abandoned by services where help could not be made available for several hours, where promises of assistance were forgotten, and where no help was directed specifically towards the carer.

### Appropriate respite

**Quotes from FGDs describing need for respite care**

‘I am 71 now ... I would like to think I have some life on my own, I wouldn’t have a career, I know that, I am too late for that ... but it would be nice to think I could pursue some pleasure ...’

‘I know it’s awful, but sometimes you wish that you could shut the door. You need some space ... It’s a relief when he is in hospital and under section, because that means that he is out of my road ... that is not the way to look at things and you feel guilty.’

Respite care was a vital need, common to all carers. To help carers, respite had to provide a realistic and practical solution, be affordable and available in emergencies, over weekends, and during holiday periods. Respite that had to be booked months in advance compromised the opportunity for spontaneity in a carer’s life. Even good-quality respite had problems: some dependants were reluctant to use it; and sometimes carers experienced guilt about their dependant going into respite.

### Diversity of needs amongst carers

Within each of the four areas of ‘common’ need described above, carers of dependants from different patient groups had specific detailed needs. An example of this is shown in relation to respite care in Fig. 1.

### Other needs identified by carers

In addition to the four key needs identified by carers across all patient groups, there were many diverse needs identified by carers from one or more patient groups. These are shown in Table 3.

### Discussion

This study has used qualitative methods to produce a detailed overview of carers’ own perceptions of their needs and has
highlighted areas in which statutory and voluntary services could play a role in meeting those needs. Although the findings cannot necessarily be viewed as representative of all carers' needs, it is likely that the inferences drawn can be generalized to carers outside the study situation, because caring is such a common experience, and because of the broadness of the themes emerging in the findings. The findings of the study are therefore of relevance to all agencies involved in commissioning and providing services for carers and their dependants, particularly if complemented by quantification and determination of priorities of the identified areas of need at a local level.

Many of the emergent themes from the focus groups related to social needs, but two areas of particular relevance to the National Health Service were carers' concerns about the response of health professionals and the need for appropriate information.

Whereas some carers praised individual professionals for their care, the overall professional response to carers was perceived as strongly negative. In relation to health services, carers generally based their opinions of professionals on those they encountered while in the caring role. For example, when carers accompanied their dependant to the doctor, they were in attendance, but had no direct locus in the consultation. Moreover, the carer may not have been registered with the same GP and would not usually have been referred to the hospital specialist. How can carers' own needs be met when they are not the focus of professional attention? The challenge for the National Health Service is to find a way to engage with
carers without requiring registration or referral in the first instance.

The perceived need for health information provides a further illustration of this point. Carers were specific about the type of information that would be helpful. They wanted direct information about their dependent’s diagnosis and management plan so that they could reach a decision about their own role in the continuing care of their dependent. They also wanted general information about how to provide care and how to obtain further help. This need for information has been identified by other studies. New carers identified health professionals, mainly doctors, as their ideal source of this information.

In addition, carers asked more of professionals than a simple delivery of information. Carers wanted a two-way dialogue with professionals in which their own contribution was valued equally with that of the professional. They wanted recognition and support for their own roles, not as additional recipients of care, but as peers with professionals in the caring process; they wanted to be able to influence their dependent’s treatment plans as they were formulated; and they wanted professionals to recognize and to provide the help that carers themselves needed. The need for a change in attitude of professionals to carers has been recognized previously.

Therefore, although the required information is readily available from health care professionals, an appropriate context for its delivery to carers is less well established. Thus carers perceived the professional response to them negatively.

This study has taken a broad-ranging approach to elicit carers’ needs and few other studies have determined carers’ needs in a way which allows comparison. Cohen and Thomas studied the self-perceived needs of carers of people with mental illness and concluded that the current system was a barrier to caring for carers. Their findings concur with the main conclusion of this study, which suggests that within health services it is the systems of service provision that need to improve to meet carers’ needs. Therefore, the challenge for the National Health Service is to find ways of enabling professionals to recognize carers at an early stage and to provide care which goes beyond the patient and ‘treats’ the carer.

In Fife, to meet this difficult challenge at a local level, a multi-faceted and multi-organizational approach was developed. First, a Fife Carers’ Strategy was developed with action plans, which included increasing professional recognition, across primary, secondary and tertiary care, of their role in engaging carers and meeting their needs. Carers’ panels were established in three distinct geographical areas in Fife. Each panel consisted of approximately 15 self-selected carers. The primary aim of each panel was to monitor and ensure the implementation of action plans developed from Fife Carers’ Strategy. They were also used for consultation of Fife Health Board service reviews and Community Care Plans. A Carers’ Information Pack was developed and circulated widely across Fife, including to GPs. Lastly, a quantitative assessment of carers’ needs was planned.

However, in addition to action at a local level, further action is required at a national level. Medical schools and professional colleges need to recognize the importance of carers and so educate their students and doctors to care for carers as an integral part of routine patient care.

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