Communication problems between dementia carers and general practitioners: effect on access to community support services

David G Bruce, Glenys A Paley, Peter J Underwood, David Roberts and Duncan Steed

ABSTRACT

Objectives: To investigate the circumstances that led general practitioners to refer dementia sufferers and their carers to community support services.

Design: Qualitative study using semi-structured interviews, carried out between 1 September 1999 and 30 April 2000.

Setting and participants: 21 live-in carers of patients with dementia referred for the first time to a Western Australian metropolitan Aged Care Assessment Team, and 19 of their referring general practitioners.

Results: Most referrals occurred after the carers had been experiencing carer stress, and were precipitated by crisis situations. Carers failed to discuss their difficulties with the referring GP for a variety of reasons, including the belief that they should cope because it was their duty. The doctors found it difficult to know how the carers were coping or when to intervene, and some carers tended to resist their attempts to help. Time constraints were a significant problem for both groups.

Conclusion: Attitudinal barriers in both carers of patients with dementia and GPs, combined with time constraints, often lead to inadequate assessment of carer problems. While it is important that strategies to improve communication between carers and GPs are developed, it would be sensible for GPs to assume that dementia carers are at risk of carer stress and should be encouraged to use community care services.

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THE PROBLEMS experienced by dementia carers have been well documented. They often experience fatigue and high levels of psychological stress,[1] and may be at increased risk for psychiatric and physical morbidity and have increased mortality rates.[2-4] While the benefits of support services such as home care or respite care remain largely unproven,[1] there is evidence to support their use, particularly when combined with carer education and counselling.[5,6]

In Australia, general practitioners are the health professionals most commonly seen by dementia carers,[7] and access to community care is usually, although not exclusively, by GP referral.[8] Despite this, lack of accurate and timely information has been cited as the most common reason why carers fail to obtain the help they need.[9]

A common route to community care is by GP referral to an Aged Care Assessment Team (ACAT), whose role is to assess the patient's need for institutional care or community support programs. In a previous study, we found that most dementia carers referred to our local ACAT had experienced lengthy periods of stress before the referral,[10] suggesting that this is an important threshold event for many local carers. Many described difficulty discussing the caring role with their doctors, suggesting that communication problems delayed timely referral. In this study, we interviewed another group of dementia carers, and also sought their GPs' perspectives, to explore the circumstances around referral to community care.

METHODS

We identified live-in carers of people with dementia living in the community who were consecutively referred for the first time to the Fremantle ACAT between 1 September 1999 and 30 April 2000. Eligible carers were identified at the weekly ACAT case-review meetings, and comprised those who lived with a patient diagnosed with dementia and had been in the caring role for at least six months. Carers and their referring doctors were invited to be interviewed by letter and follow-up telephone call.

All interviews were carried out by the same researcher (G A P), who was not a member of the ACAT or other health service provider. Interviews with carers took place in their homes. Interview questions included the duration of the relatives' dementia, duration of care, duration of carer difficulties, the nature of any problems with the caring role, the nature of the relationship with the GP, and an exploration of possible triggers that led to the ACAT referral. Carers were asked to fill in the scaled 28-item General Health Questionnaire (GHQ-28) as a gauge of possible carer stress.[11]

GP interviews took place within their surgeries or by telephone. Interview questions explored similar topics to those listed above, as well as GPs' knowledge of the carers' problems. The doctors' referral letters were assessed for evidence of perceived carer stress and the urgency of the referral.

Analysis

Taped interviews were transcribed and read twice by at least two researchers

Department of Medicine, University of Western Australia, Perth, WA.
David G Bruce, MD, FRACP, Associate Professor; **Glenys A Paley,** BSc, Dip Hlth Prom, Research Officer.
Department of Health Sciences, Curtin University, Perth, WA.
Peter J Underwood, MB BS, PhD, Professor.
School of Nursing, Edith Cowan University, Churchlands, WA.
David Roberts, RN, PhD, Senior Lecturer.
Fremantle Regional Division of General Practice, Fremantle, WA.
Duncan Steed, MB BS, Chief Executive Officer.
Reprints will not be available from the authors. Correspondence: Assoc Prof David G Bruce, Department of Community and Geriatric Medicine, Fremantle Hospital, PO Box 480, Fremantle, WA 6959. dbruce@cyllene.uwa.edu.au

(GAP, DGB or DR) and coded by means of computer software.[12] All authors (three are experienced qualitative researchers) re-read transcripts and discussed the interviews to identify and categorise important themes.

Ethical approval

The study was approved by the Fremantle Hospital Ethics Committee and participants signed a consent form.

RESULTS

The carers of 28 consecutive referred patients were invited and 21 agreed to participate. Those who refused cited lack of time or being too stressed as reasons. There were 16 spouses (seven wives, nine husbands), four children (three daughters, one son) and one sister. They were aged 43–83 years (mean age, 68 years). Two carers refused or failed to return the GHQ-28.

Two GPs refused to participate. The 19 participating doctors were aged 34–66 years (mean age, 48 years), and 12 were male. All doctors had been the patient's usual GP for at least six months, and 14 also cared for the carer.

Carer stress

Carers estimated that the duration of care was six months to seven years (average, 2.3 years). Carer estimates of the time they first consulted a GP about the dementia ranged from six months to 6.5 years previously (average, 1.8 years). The average score for the 19 carers who completed the GHQ-28 was 7 (range, 0–24); 10 had scores over 5, consistent with their having a mental health problem such as anxiety or depression.[13] Common problems for carers emerging from the interviews included the patients' difficult behaviours, their own exhaustion, feeling stressed, and lack of time for personal or social activities.

Referrals

Most of the doctors' referral letters included the word "urgent" or described carers failing to cope or being under severe stress. The interviews showed that a variety of triggers precipitated referrals, including GP recognition of deterioration in the patient's condition, new behaviours (wandering, incontinence) and a decline in the health of the carer.

Several factors that delayed referrals were identified during the interviews. These are described below.

Carer perceptions of caring (see Box 1): Many carers reported feeling that they should have been able to manage without outside assistance, often describing a sense of duty towards their partner. Some expressed pride in their efforts, while others felt guilty for accepting formal support services. Other reasons given that prevented them seeking community support included the dementia sufferers being resistant to the idea, carers being in denial about their partner's dementia, and concerns about using scarce resources before absolutely necessary. Several carers stated that, with hindsight, they wished they had sought care sooner than they had.

Carer perceptions of the GP (Box 2): Most carers expressed satisfaction with their GPs, and, although some indicated problem areas, only one expressed dissatisfaction with her doctor. Many commented on how busy their doctors were, that they tended to concentrate on medical matters, and that they seemed unaware of the carer's problems. Several carers thought that their GP was not sufficiently aware of support services or was unskilled in dementia care. Some commented adversely on the need to prompt the doctor for a referral. A few carers had changed doctors in order to get better attention.

The GP role: All GPs stated that their role was to support the family by providing information, being prepared to discuss problems and by acting as coordinators of specialists and support services. Most felt that lack of time was a

1: Carers' perceptions of caring and community care

Carer	Circumstance	Comments
No. 6 — husband, aged 80	Urgent referral for respite	*"…now I realise I should have got a bit of help whilst she was home here; she might still be here."*
No. 7 — son, aged 50	Father admitted to nursing home shortly after referral	*"We believed we were coping; we are not a family that looks after handouts."*
No. 13— husband, aged 77	Wife with mild dementia, no formal support services	*"I'll go on doing…until I can't any more…It is a matter of pride."* *"Respite care will be good for me…but not for my wife. She feels…I will be deserting her."*

2: Carers' perceptions of their general practitioners

Carer	Circumstance	Comments
No. 2 — husband, aged 83	Wife has moderate dementia and incontinence	*"The doctor…does what he can to help…the only problem is he is so damn busy."*
No. 3 — wife, aged 73	Occasionally aggressive husband	*"I don't like asking him…he shouldn't be filling out forms…although he doesn't seem to mind…he's busy whether he's paid or not."*
No. 16 — wife, aged 52	Husband with serious behavioural disturbances; urgent referral for respite care	*"He gave me absolutely no information; I didn't have a clue where to go…it was like trying to get blood out of a stone."*
No. 21 — husband, aged 78	Wife with severe dementia	*"…I had to prompt her; you always have to prompt GPs…"*

3: General practitioners' perceptions of the carers

Carer	Circumstance	Comments
No. 2 — husband, aged 83	Urgent referral; wife disoriented and incontinent	*"He was coping quite well, that was my impression…maybe I didn't ask the right questions."*
No. 8 — wife, aged 57	Carer herself confined to a wheelchair	*"So we've left it for the time being to see if something happens that gets us involved."* *"Sometimes we concentrate on the patient…and ignore the carer who may be suffering…"*
No. 13 — husband, aged 77		*"I have to pull the words out of him…I need to give all the suggestions."*
No. 21 — husband, aged 78	GP noted carer exhaustion, wife awaiting nursing home placement	*"Even though I gave him opportunities to [talk]…there was almost denial…and he was struggling to cope, but I think he saw it as threatening, that somehow he was letting his wife down."*

problem, leading to inadequate assessment and diagnostic difficulties. Lack of remuneration for the time required was reported by a few.

GP perceptions of carers (Box 3): Several GPs reported that carers resisted their suggestions about seeking assistance, and that they insisted they were coping even when the doctor believed otherwise. Some doctors found that the carers were reluctant to discuss how they were managing, perhaps because they were worried about wasting the doctor's time. Many doctors found it difficult to decide when to intervene. Some were disinclined to intrude too soon (*"…I usually wait for the problem to be quite severe; I don't get involved too early"*) or at all (*"If they don't bring up the problem, why should I?"*).

DISCUSSION

The dementia carers we studied were first referred to community care services when they had considerable carer stress, often at a time of crisis. This occurred despite there being opportunities for carers and GPs to discuss the carer's situation. While many individual factors inhibited the interaction in the GP's surgery, several important themes were identified.

One of these was a strong sense of duty among carers towards their affected relative that drove them to continue caring for as long as possible without outside help. This sense of duty was a potent inhibitor that coincided with the dementia patients' unwillingness to accept community services. These factors probably explained carers' reticence to discuss problems and their reluctance to consider outside assistance, as experienced by the GPs. Additionally, carers were inhibited from broaching the subject with their doctors because they seemed too busy, uninterested or preoccupied with medical matters. The communication breakdown was exacerbated by the time constraints of the GP consultation and led to a crisis-driven approach to dementia care.

While it is difficult to generalise from qualitative data, our findings are consistent with difficulties reported previously by Australian GPs,[13] and with reports that family carers in the UK are stressed when they seek help,[14] that carers do not use services when they think they can cope,[15] and that GPs have difficulty detecting psychosocial problems in their patients.[16]

Improved communication between carers and GPs would benefit both carers and dementia patients. Potential strategies could make use of the Enhanced Primary Care Medicare items, although a recent study did not find that this improved psychosocial management.[17] Another approach would be to use health promotion techniques to encourage carers to discuss their problems with GPs, and we are testing this in Perth. Nevertheless, given the difficulties in detecting carer stress and the extent of the communication barriers, we recommend that GPs assume that carers of patients with dementia are at risk of carer stress, and that they attempt to get them involved with appropriate support services.

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COMPETING INTERESTS

None identified.

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