

## Research paper

# Proactive primary care of carers of people with cognitive impairment: a feasibility study

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## ABSTRACT

**Background** Over 250 000 Australians live with dementia, and it is estimated that this number will more than double by 2030. Many people with dementia or cognitive impairment are cared for at home by family carers who may themselves be frail older adults or who may suffer from chronic conditions. There is evidence that caring has adverse impacts on carers; however, many do not seek or delay seeking appropriate health care.

**Aim** To explore the feasibility of a protocol to identify the unmet healthcare needs of carers of people with cognitive impairment.

**Method** This feasibility study used a mixed-methods approach. Data were collected through a set of three wellbeing questionnaires, and interviews with carers and one general practitioner. Carers were recruited through government-funded adult day care centres in Perth, Western Australia. General practitioners were nominated by the carers. The sample included 15 carers and one general practitioner.

**Results** Carer participants in this study experienced varying degrees of care burden. Insomnia, fatigue and pain were the most prominent symptoms. Their overall health status was lower than that of the general population, with physical functioning and bodily pain obtaining the lowest scores. Carers found the protocol useful and the questionnaires easy to complete; they reported specific outcomes resulting from the implementation of the protocol aimed at addressing their healthcare needs.

**Conclusion** The study results demonstrate the feasibility of adopting a protocol to identify and address carers' unmet healthcare issues, and warrant further research. In the context of an ageing population, the growing number of carers of people with cognitive impairment and dementia need to receive adequate support to enable them to continue to provide care.

**Keywords:** carers, cognitive impairment, primary care, unmet needs, wellbeing

## How this fits in with quality in primary care

### What do we know?

Carers have many unmet healthcare needs, and are at risk of suffering morbidity and premature mortality. Not seeking or delaying early treatment impacts negatively on the carer's wellbeing, but ultimately also on the person who is dependent on the health and wellbeing of their carer.

### What does this paper add?

Carers of people with cognitive impairment need to be supported to continue to provide care. Providing carers with tools to discuss their healthcare needs with their general practitioners may be an effective proactive management strategy.

## Background

Over 250 000 Australians live with dementia, and it is estimated that this number will increase to almost 591 000 by 2030.<sup>1,2</sup> Mild cognitive impairment (MCI) is a syndrome that is currently considered a potential transition phase between healthy cognitive ageing and dementia;<sup>3</sup> it is estimated that more than 50% of people showing signs of MCI later develop dementia.<sup>3,4</sup>

The proportion of the population caring for a spouse, relative or friend with a chronic and complex condition is increasing.<sup>1</sup> Many people with dementia or cognitive impairment are cared for at home, and are supported by family carers who may be frail themselves or suffer from chronic conditions.<sup>5</sup> Evidence shows that caring can have adverse psychological, physical, social and financial impacts on the carer;<sup>6</sup> carers have many unmet needs and suffer morbidity and premature mortality.<sup>7,8</sup> However, the caring role is often to the detriment of the carer's own health needs.<sup>7</sup> Thus, many carers who experience symptoms or health issues do not seek or delay seeking appropriate healthcare.<sup>9</sup> Failure to seek early treatment not only impacts negatively on the carer's wellbeing, but, ultimately, also on the person with cognitive impairment, who is dependent on the optimal health and wellbeing of their carer.<sup>10</sup> The need for a proactive approach to addressing the physical and mental health needs of carers has been highlighted,<sup>11</sup> especially as health practitioners may be unaware of the impact of the burden of care on their carer patients.<sup>12</sup>

This research aimed to investigate the feasibility of implementing a protocol to identify the healthcare needs of carers of people with cognitive impairment, and to support general practitioners (GPs) in addressing these needs. The outcomes of this feasibility study will inform a larger pilot study.

## Method

The design of this feasibility study was informed by the Medical Research Council's framework for the development and evaluation of complex interventions. This framework consists of five phases: (1) pre-clinical or theoretical; (2) modelling; (3) exploratory trial; (4) main trial; and (5) long-term surveillance;<sup>13</sup> and has been found to be easily applied in practice.<sup>14</sup> Data were collected from August to September 2011 and written consent was obtained from all participants.

The intervention piloted in this study incorporated the following components: the administration of a series of instruments aimed at assessing carers' health and wellbeing; one GP consultation aimed at discussing the impact of carers' care-giving role using the results of the completed instruments as a starting point; and a toolkit designed to support GPs to address the specific needs of carers of people with cognitive impairment.

People who identified themselves as the primary caregiver of a person with cognitive impairment, were aged 18 or over, and could nominate a usual GP were invited to take part in the study. Participants were recruited through Home and Community Care (HACC)-funded adult day centres in the metropolitan area of Perth, Western Australia. Service co-ordinators provided potential participants with recruitment flyers and invited them to contact the research team. Approximately 225 recruitment flyers were circulated.

Participants completed a demographics questionnaire and three wellbeing questionnaires: the Zarit Caregiver Burden Interview (ZCBI);<sup>7</sup> the European Organisation for Research and Treatment of Cancer: Quality of Life Questionnaire (EORTC-QLQ30);<sup>15</sup> and the Short Form 36 Health Survey (SF-36® v2.0).<sup>16</sup> The 22-item ZCBI questionnaire was developed to measure the level of burden experienced by caregivers of older people with cognitive impairment; the higher the resulting score, the greater the carer burden.<sup>7</sup> The EORTC-QLQ30 incorporates nine multi-item scales: five functional scales, three symptom

scales, and a global health and quality of life scale. A higher score for a functional scale item indicates a higher or healthier level of functioning, and a higher global health score indicates a higher quality of life; a higher score for a symptom scale item indicates a higher level of symptomatology.<sup>15</sup> Although EORTC-QLQ30 was originally developed to measure quality of life among cancer patients, this questionnaire was selected for this feasibility study because of its high reliability and validity, and because it can easily be completed without assistance. Finally, the SF-36<sup>®</sup> v2.0 has been widely used to describe and monitor general health and wellbeing. The instrument incorporates eight items grouped around a physical component (physical functioning, role physical, bodily pain and general health) and a mental component (vitality, social functioning, role emotional and mental health).<sup>16</sup>

Eligible participants were offered the choice of either completing the questionnaire themselves or receiving a visit from the research team to assist with completion. Those who chose self-completion were mailed a pack including the following: information sheet; consent form; copies of the demographics and three wellbeing questionnaires; reply-paid envelope; and completion instructions. Participants who opted to receive assistance were visited by the research team at a venue of their choice. Participants were encouraged to visit their nominated GP within four weeks of completing the questionnaires to discuss their caregiving role using the completed questionnaires as a starting point. In Australia, GPs are private practitioners and therefore able to charge a fee for their services. In this case, the charge to Medicare could have included a long consultation fee and a 'care plan' in any case where the GP determined that the patient required the services of an allied health professional. Four weeks after completing the questionnaires, participants were contacted by telephone and invited to provide feedback on the process and on any specific outcomes resulting from the implementation of the protocol.

Nominated GPs received an initial letter informing them of their patient's involvement. Within a week of the initial contact, GPs were mailed study information, a consent form and a GP Toolkit. The toolkit – based on an existing GP Care-giver Toolkit developed for and successfully trialled with carers of people with advanced cancer<sup>17</sup> – was amended to reflect the specific needs of carers of people with dementia, and was developed in consultation with Alzheimer's Australia WA. The toolkit included: copies of the self-assessment tools used by study participants; a list of support services and resources; *Lifescrpt* resources (Lifescrpts: evidence-based tools to support general practices across Australia to work with patients to address lifestyle risk factors for chronic disease) and

guidelines for discussing end-of-life issues. Participant GPs were contacted by telephone and invited to provide feedback on the process and on the GP Toolkit. No fee was offered for this interview.

Quantitative data from the ZCBI and EORTC-QLD questionnaires were analysed using Statistical Package for the Social Sciences (SPSS) software, while Quality Metric Health Outcomes<sup>™</sup> was used for the analysis of the SF-36<sup>®</sup> v2.0 questionnaire. Qualitative data from interview notes were subjected to content analysis.

## Results

A total of 15 carers took part in the study; given that two potential participants were ineligible, this represents a response rate of 7.6% (17/225). The majority of carers ( $n = 12$ ) opted to receive a visit from the research team to assist with completion, while the remainder ( $n = 3$ ) chose self-completion. Of the 15 participants who completed the questionnaires, 13 took part in the follow-up interview. The majority of carers were female ( $n = 13$ ), and their mean age was 70.9 years. The sample is somewhat inconsistent, with Australian data on carers of people with dementia suggesting that approximately 75% of carers of a person living with dementia in the community are women and approximately half are aged 65 and over.<sup>18</sup> Engagement of GPs proved difficult to achieve; six GPs consented to be part of the study. However, despite several attempts, only one could be contacted and interviewed.

The analysis of the ZCBI scores showed that participants experienced varying degrees of carer burden: four participants experienced either little or no care burden (score 0–20), three mild-to-moderate burden (score 21–40), six moderate-to-severe burden (score 41–60), and one severe burden (score 60–88). One participant did not complete this questionnaire.

Table 1 shows carers' mean EORTC-QLQ30 scores for the total sample. Insomnia, fatigue, pain and constipation were the symptoms with the highest scores, indicating greater issues around those areas. With regard to the functional scale items, the mean scores indicated a lower level of functioning around 'role' and 'emotional' functions. Carers' mean SF-36<sup>®</sup> v2.0 scores are shown in Table 2. The physical component summary score indicates an overall health status below that of the general population, with physical functioning and bodily pain the sub-components obtaining the lowest scores. By contrast, the mental component summary score was slightly above the average, although vitality and social functioning had comparatively low scores.

**Table 1** Mean EORTC-QLQ30 scores ( $n = 15$ )

Scale item	Mean score
<b>Symptom scale item†</b>	
Fatigue	37.0
Nausea and/or vomiting	2.2
Pain	31.1
Dyspnoea	4.4
Insomnia	50.0
Appetite loss	4.4
Constipation	26.7
Diarrhoea	2.2
Financial problems	6.7
<b>Functional scale item‡</b>	
Physical function	80.0
Role function	63.3
Emotional function	63.5
Cognitive function	75.6
Social function	88.9

†: score range 0–100, a higher score indicates a higher level of symptomatology/problems. ‡: score range 0–100, a higher score indicates a higher/healthier level of functioning.

**Table 2** Mean SF-36® v2.0 scores ( $n = 15$ )

Scale item	Mean score†
<b>Physical component summary</b>	
Physical functioning	44.83
Role physical	48.98
Bodily pain	46.12
General health	51.09
<b>Mental component summary</b>	
Vitality	47.19
Social functioning	48.67
Role emotional	50.60
Mental health	51.22

†: scores generally range from 20–70; scale scores below 50 indicate health status below general population level.

Evidence from the survey instruments contrasted with carers' perception of their own health and wellbeing. Thus, although some carers reported health issues such as high stress levels, back problems or walking difficulties, the majority indicated that their health was 'fine' and they were coping well. Furthermore,

some carers spoke of their coping strategies. For example, one male carer reported:

'I've set up a small woodworking workshop just off the lounge so that I can do some work alone while my wife watches TV. I can hear if she needs me and it gives me time by myself.'

Carers generally found the questionnaires easy to complete; they also reported that completing them had made them reflect on their own needs. Most carers ( $n = 11$ ) visited their GP after completing the self-assessment questionnaire. Reasons given for not making a GP appointment included long travelling distance and failing to understand the process. One carer said that she had visited her GP too soon, and the GP had not had time to read the Toolkit; another carer reported that their GP did not have time for a long appointment to review the protocol.

Carers' perception of the usefulness of the protocol varied; for some it was an opportunity to reflect on their own health and wellbeing and discuss their concerns with their GP, while some thought the protocol had not resulted in any major change, as they felt they were already 'coping well'. One carer stated that this process 'would be useful to people who weren't coping as well'. Carers reported specific outcomes resulting from the implementation of the protocol and their conversation with their GP; these included the following: a referral to follow-up on a back problem; a physiotherapist home visit; respite arrangements for the person with dementia; and information on how to access HACC-funded domestic assistance. One carer reported that although her GP had suggested respite care for her husband, she had declined; she added: 'what would [my husband] think if I put him in care?' Finally, another carer was concerned about her husband's ability to drive; however, she was unable to discuss this matter with her GP because her husband was present at the appointment.

## Conclusion

Results from this feasibility study demonstrate a limited potential for adopting this protocol to identify and meet the healthcare needs of carers of people with cognitive impairment. While the majority of carers made an appointment to see their GP, a limitation of the protocol was the lack of success in engaging with GPs to gain an insight from their perspective. A systematic review recently published in this journal focused on strategies to engage primary care practitioners in research.<sup>19</sup> The review offers the following guidance:

- 1 Deploy opinion leaders as project champions. In this case, it may be helpful to engage with local experts in dementia care to act as ambassadors for the project and to involve these leaders in local media publicity about the project.
- 2 Engage local primary care organisations to host the project, for example the Medicare Locals, which represent groups of general practices in regional areas of Australia.
- 3 Offer continuing medical education points and financial recompense for participating in the project generally and in interviews in particular.

Such strategies have been thought to improve the possibility of engaging with GPs on other similar projects. Another strategy that is being considered is to test the intervention further with the use of standardised patients (carers) and a relatively small group of volunteer GPs. This has been previously reported to be an acceptable research strategy in testing whether a complex intervention such as this can be assimilated into general practice.<sup>20,21</sup>

Consistent with other research,<sup>8–10</sup> results from this study suggest that carers of people with cognitive impairment have unmet health needs. We noted that the carers were unwilling to discuss their needs with a GP when the person with cognitive impairment was present in the consultation. Therefore, in any future study carers would be strongly advised to make an appointment when it was possible for them to attend alone. Furthermore, the toolkit will be amended with the advice to practitioners to be aware that carers have been known to be reticent about discussing their needs when the person they are caring for is present. In most cases, it may be possible for the practitioner to ensure that he or she is able to discuss the issues in private, even if the person being cared for has accompanied the carer to their appointment.

In the context of an ageing population and the growing recognition of the need to support older people to maintain their independence and continue to live at home, carers of people with cognitive impairment and dementia need to receive the support they require to enable them to continue to provide care. Further research is warranted to explore the role of carer and how this role evolves over time following diagnosis, and how carers can be best supported in their caring role at each stage of their journey.

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#### PEER REVIEW

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#### CONFLICTS OF INTEREST

None.

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