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Caring for carers of people with dementia: can we do it by videoconference?

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Abstract

Background: In rural Australia, there is unmet need for knowledge and support by informal carers of people living with dementia. Support from family and friends plays an important role in maintaining caregiving activities. Post-care, these social networks assist carers to adjust to their change of role and to deal with grief. Improving access to peer support for carers can enhance their ability to effectively cope with the challenges of caring. This project trials a videoconferencing-based peer support program, to connect carers with other carers. However, an essential task for progress of any community-based project is recruiting people to be involved, and carers of people with dementia are known to be difficult to recruit to research.

Aims: The aim of this paper is to describe the strategies we are using to recruit carers to the Caring for Carers program, and how successful these have been.

Methods: Participants are recruited to the project using a range of strategies at the macro, mesa and micro levels, with varying success.

Results: We contacted 80 national and state peak bodies, 471 local councils, service providers, and community groups, and made over 200 contacts (mainly in Queensland) with individuals. We were contacted back by 134 interested people, 122 of whom were eligible for participation in the study; and 67 carers of people with dementia (55%) agreed to take part.

Conclusion: In the face of unmet need, and continued reinforcement of that need when we do connect with carers, being able to connect with isolated carers by any mode can be challenging.

Keywords: rural, carer, dementia, research subject recruitment

Policy implication: Recruitment of an adequate of participants to studies with carers of people with dementia is challenging. Given the importance of research with this group, a centralised database of people with dementia and their carers is needed.

Introduction

In rural Australia, knowledge about availability of services and resources for informal carers and utilisation of these supports by carers can be inadequate (1). Carers of people with dementia can find the social welfare and aged care systems complex, and they may have difficulty finding out what services are available (2). Support from family, friends and community can play an important role in maintaining caregiving activities. Post-care, these social networks assist carers to adjust to their change of role and to deal with grief. Improving access to peer support for carers can enhance their ability to effectively cope with the challenges of caring. Access to support can be limited for carers who have difficulty separating from the person they care for, particularly for those living in rural areas (3). New information and communication technologies can provide opportunities for developing and maintaining social contacts and support networks (4) (5) (6). This project trials a videoconferencing-based peer support program, to connect carers with other carers, the Caring for Carers of People with Dementia Program (7).

An essential task for progress of any community-based project is recruiting people to be involved. Recruiting carers of people with dementia is acknowledged as difficult (8-11). It has been estimated that approximately 10% of people with dementia in the United Kingdom would agree to participating in a drug trial (12), and, although this could not be estimated from the available evidence, the authors suggest that people with dementia and their carers might be more likely to participate in non-drug trials. A recent Australian study used Google Adwords to recruit family carers of people with dementia to complete a survey on their wellbeing (13). Although the ads were viewed more than 450,000 times in a six-week period, only 49 surveys were completed, at a cost of \$122 per survey. The proportion of clicks resulting in participation in this study was only 3.25%, although the authors conclude that the length of promotion was too short and the ads were too non-specific, attracting formal as well as informal carers (13). A study from the United States of America (USA) suggested that major barriers to recruiting carer/caree dyads were lack of connection to services and gatekeeper behaviour at referring organisations (10). They suggested phone screening and staff well-trained to communicate with the participant group as strategies to increase recruitment. Another study from the USA compared direct mail, newspaper advertisements, and community outreach for recruiting dyads, finding that direct mailings was the most effective and least costly method of recruitment (8). However, this strategy presupposes an appropriate mailing list or strong support from aged care organisations. All studies agree that recruitment of this group remains difficult.

The aim of this paper is to describe the strategies we are using to recruit carers to the Caring for Carers program, and how successful these have been.

Methods

Design

The project uses a randomised wait list design, following a 15 week evaluation cycle: 1 week baseline assessment, 6 weeks active intervention/waitlist, week 8 mid assessment, 6 weeks post intervention/active intervention, week 15 post-test, and week 26 follow-up (14).

Participants, interventions and measures

Study setting: The project is Australia-wide, and community based. However, three rural areas of Queensland, Australia are a specific focus: Wide Bay and Burnett, Central Queensland, and Cairns Hinterland.

Eligibility criteria: Participants are isolated Australian primary carers of older people with dementia. Participants must have access to an internet connection.

Interventions: A videoconferencing-based peer support program was co-designed with carers of people with dementia. The core intervention activity is a series of six interactive videoconferencing sessions. Groups are encouraged to continue meeting after the 6-week program.

Outcomes: The primary outcomes for the overall project are changes from baseline for self-efficacy, quality of life and mental health of carers.

Recruitment measures: The recruitment measures are number of organisations and people contacted and number of carers recruited to the study.

Sample size

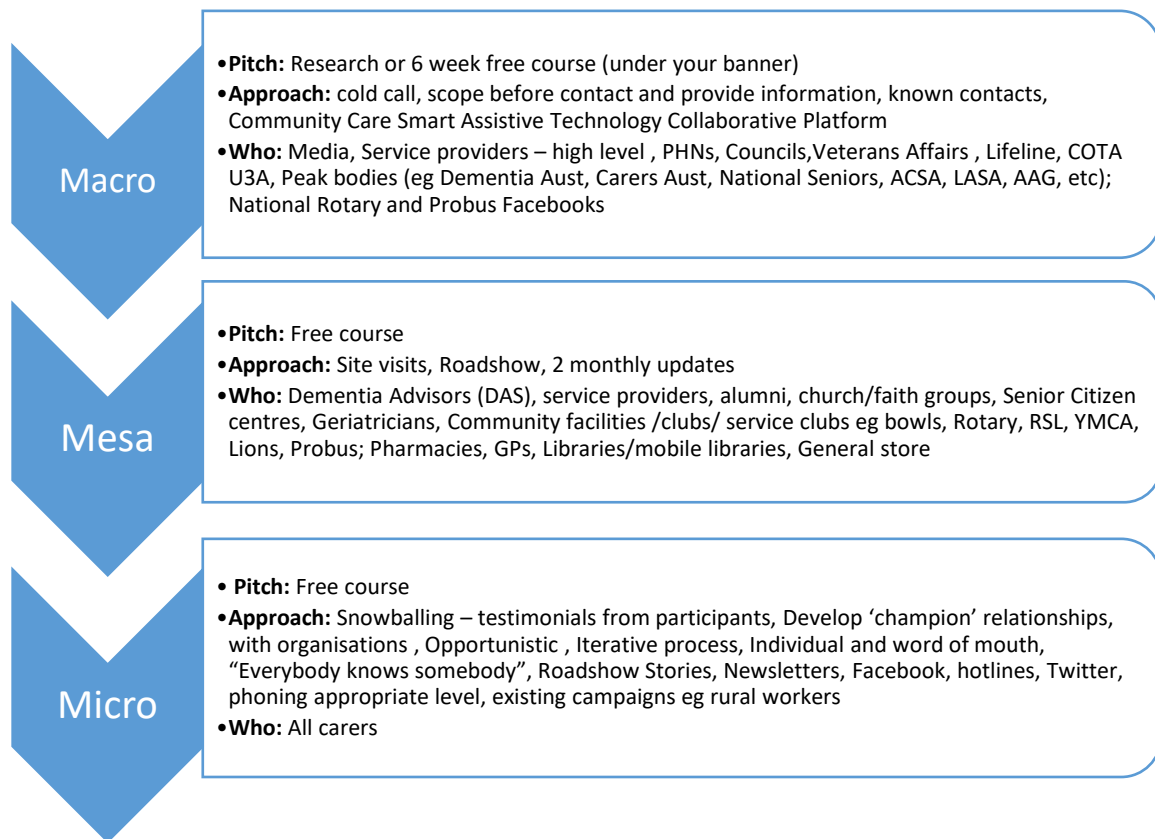
We are planning a study with 65 pairs of subjects (130 people). Early data indicated that the difference in the response of matched pairs is normally distributed with standard deviation 1.9 for the continuous self-efficacy variable. We will be able to detect a true difference in the mean response of matched pairs of $-.776$ or $.776$ with probability (power) 0.9. The Type I error probability associated with this test of the null hypothesis that this response difference is zero is 0.05.

Recruitment

Participants were purposively recruited through community organisations and networks. All participation is voluntary and informed consent was obtained.

Multiple overlapping strategies have been used to engage with potential participants to recruit and maintain involvement. See Figure 1 for the marketing and promotion plan. Strategies include macro level activity such as Press Releases for mass media report and contacts with National and State peak bodies; mesa level activities such as visits to local areas (in Queensland and NSW) and a Roadshow; and micro level activities such as Facebook.

Figure 1 Marketing and Promotion Plan for Caring for Carers Project



Data collection and analysis

Data collection methods

All contacts for recruitment and about recruitment were monitored and noted throughout the project.

Statistical methods

Counts of contacts and recruitment success are detailed. No statistical tests were undertaken.

Ethics

Research ethics approval

Ethical approval for the project was obtained from CQUniversity’s HREC (Application references: 0000020738, 0000020926).

Consent

Informed written consent is obtained from all participants. This can be returned to the Project Officer by mail, email, phone or to a Post Office Box. All consent information is stored in electronic format, separate from data.

Results

The recruitment team included authors LP, AB, AL, and KF, staff from Global Community Resourcing, an industry partner, and Communications Staff from CQUniversity.

Table 1 details the number of contacts made across the promotion model levels. Marketing macro and mesa contacts usually involve a phone call and emailing the project brochure (which includes a participant contact form) for distribution to mail lists and networks. Many organisations have Facebook pages, so can agree to promote the program there, or circulate regular newsletters where a short promotion can be added. Local Councils often provide local contacts to community organisations and information about planned relevant events. These contacts were predominantly made by KF, the Senior Project Officer. Direct contacts with people are within the context of events and attendance at carer meetings during site visits. More than 25 site visits were undertaken between March 2018 and March 2019.

Site visits were mainly undertaken by LP, AL, AB, and KF, and staff from Global Community Resourcing. LP undertook a series of Roadshows to more remote Queensland localities. AL and staff from Global Community Resourcing promoted the project during extensive travel for other projects. AB and KF undertook further promotion activities in Northern NSW.

Table 1 **Contacts across marketing and promotion levels**

Level	Where	Number*
Macro	National and State Peak Bodies	80
Mesa	Local councils; service providers, community groups	471
Micro	Direct contacts targeting individual level	~200

* Up to November 2018

Table 2 details media, social media and paper resources. Several Press Releases were sent to coincide with events, such as the Launch of the project, presided over by the Minister for Aged Care, and many of the site visits undertaken. Posters and brochures were mailed and distributed face to face. Posters were provided to General Practices, libraries and community centres during site visits.

Table 2 **Media, social media and paper resources**

Type	Number*
Radio interviews	78
Newspaper articles	20
TV interview	1
Facebook own posts	36
Facebook others posts	31
Tweets	11
Community Care Smart Assistive Technology Collaborative Platform	12
Brochures	7500
Posters	450

* Up to November 2018

Table 3 details contacts from participants, and consent status from those contacts. Contact with the team could be made by returning the completed brochure by email or post, phoning or emailing the team or completing a contact form on our website. The vast majority of contacts come through the website. Of 134 people who have contacted us, 12 were ineligible. Of the 122 eligible contacts, 67 have consented to participate (55%) and 37 (30%) have not consented (mainly due to issues with their own health or loved one's health, or lack of time). Another 18 carers (15%) would like to

participate at some time but have not yet consented. In our experience, some carers can take six months or more after their first contact with us before they consent, due to life circumstances.

Table 3 **Contacts and consent status**

Contacts (total)	134*
Consent	67
Active participants	59
Consent Pending	18
Non consent	37
Not eligible	12

* Up to February 2019

Discussion

This paper describes the strategies used to recruit carers to the Caring for Carers program. A formal marketing and promotion plan, including strategies at the macro, mesa and micro levels was implemented, with a focus on Queensland but promotion across Australia. We contacted 80 national and state peak bodies, 471 local councils, service providers, and community groups, and made over 200 contacts (mainly in Queensland) with individuals. We were contacted by 134 interested people, 122 of whom were eligible for participation in the study; and 67 (55%) carers of people with dementia agreed to take part.

In 2015 there were over 200,000 informal carers in Australia (15). The vast majority of those carers would live in urban areas, which were not our focus. However, we could not identify any statistics about numbers of carers outside urban areas, so we are uncertain of the denominator to calculate our study response rate, which is a limitation of the study. This equation would be further complicated by our focus on isolated carers. However, we suspect we did not attract the 10% of carers estimated as possible in a previous UK study (12) and may in fact have not reached the 3.25% achieved by our Australian colleagues (13). We have only recruited active participation of 52% of the sample size needed, and we are nearing the end of our recruitment. We are however, recruiting to a study that requires a considerable commitment, say up to 15 hours of participant time, and includes interfacing with perhaps an unfamiliar technology (14).

We do not currently have the detail about how effective or costly each strategy has been, as we have overlapped the strategies, and unpacking this detail will take some time, another limitation of the study. When site visits happen, we know there is usually a jump in recruitment, as when a new Facebook story or a video is uploaded. However, we acknowledge that the effort of promotion is enormous compared to the outcome of number of active participants.

We did not try a direct mail approach, and focused mainly on networking and community outreach for recruiting carers, although direct mailings have previously been found to be an effective and less costly method of recruitment (8). Unfortunately there currently is no centralized database of people with dementia and their carers, although these are being planned for the near future (16), so this approach will become more possible soon.

Conclusion

Similar to other researchers, we found that recruiting carers of people with dementia is very difficult (8-11). We were also seeking the less connected, more isolated carers, in rural areas, where services may be less accessible, and the means to connect with carers are less obvious. Despite the unmet need we had identified (1), and continued reinforcement of that need when we did connect with carers, being able to connect with isolated carers by any mode was challenging.

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Presenter

Professor Lynne Parkinson is a gerontology researcher, Editor in Chief of the *Australasian Journal on Ageing*, Fellow of the Australian Association of Gerontology, and Chair of the Queensland Division of the Australian Association of Gerontology. Her current main research streams are: optimising healthy ageing with chronic disease, including quality use of medicines; and integration of rural aged care practice and service delivery.