

Australian Journal of DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

Coaching improves carer responses, health, well-being

The vast majority of older people wish to remain living in their own home in the community (Australian Institute of Health and Welfare (AIHW 2013). Much of the desire to 'age in place' is related to emotional and social attachment to the locale, and highlights the importance of creating sustainable communities which provide enabling and connected environments for older people. People value their independence but want to remain connected to others.

Of the more than 1.2 million Australians aged 65 years and over, about 80% need assistance to remain living in their own home and close to three-quarters use unpaid informal family support (Australian Bureau of Statistics (ABS) 2013). Around 60% of Australians with dementia are living in the community, with the majority being supported by 6.2 million informal carers (AIHW 2013). While families are generally willing to take on the caring role for a person with dementia (PWD), this is not easy or straightforward. Carers can find their relationship with the PWD becoming unpredictable and strained, especially when having to constantly adapt to the person's changing cognition, abilities and behaviour (Pinquart & Sorensen 2003).

What can help family carers?

Without extended family and community support in this demanding role, the carer's physical and psychological health can break down.

Continuing carer stress can ultimately lead to abuse and/or neglect of the PWD. This situation can be helped with carer education and support.

The particular things that family carers find beneficial are knowing how and where to obtain help in the caring role (Burgio *et al* 2009), how to adapt to and manage the PWD's changed behaviour and abilities (Rosness *et al* 2011) and how to maintain their own health and well-being (Thompson *et al* 2007). These can be achieved by developing self-efficacy in the caring role (Rabinowitz *et al* 2009), ie having belief in one's emotional capacity, knowledge and skills to undertake the caring role and in responding to changed circumstances. Holding the belief that personal behaviours will influence the achievement of goals in the caring role is one of the key motivators for doing so (Au *et al* 2010).

The carer coaching program

This article reports on a study to introduce and evaluate an evidence-based caregiver

Family and community support, as well as education, are vital to the continued health and well-being of carers, especially those from CALD backgrounds, who may feel alone and isolated.

Lynn Chenoweth reports on a successful Australian carer coaching program for families living with dementia that, among other positive outcomes, has encouraged carers to seek mutual support and use respite services for the first time

coaching program, provided by community nurses and social workers in Sydney, NSW (Chenoweth *et al* 2016).

The Carer Coaching Program for Families Living With Dementia aimed to help carers of people with mild to moderate dementia living at home to:

- develop self-efficacy for the caring role
- be less hassled by the caring role
- pay attention to their health needs
- improve their health and well-being; and
- use goal-directed behaviour to identify and meet their needs.

Coaching was offered to family carers of people with dementia by trained nurses and social workers (some of whom were bilingual in English and Cantonese and/or Mandarin) from six Australian community-based dementia carer support services

A convenience sample of 91 family carers of people with a moderate to severe level of

dementia who were new clients of these carer support services consented to participate in coaching immediately (intervention group), or to continue with usual carer support and undertake coaching four to six months later (comparison group). To be eligible for coaching, carers were required to provide daily care and/or support to the person with dementia (scoring between 10-23 on the Mini-Mental State Examination (MMSE) (Folstein *et al* 1975) (fluent English speakers), or scoring 16-22 on the Rowland Universal Dementia Assessment Scale (RUDAS) (Storey *et al* 2004) (non-fluent English speakers), and to be able to understand spoken English. As the majority of carers were 65 years or older, they were also required to have a score of 0-1 (out of 5) on the five-item Geriatric Depression Scale (Rinaldi *et al* 2003).

What specific coaching occurred?

The coaching program was based on self-efficacy theory

(Bandura 1997), offered as seven learning modules: self-efficacy in the caring role; self-determined goals; adapting to the caring role; self-care and self-help; person-centred care; relationship building; and accessing informal and formal support.

The 14 nurses and four social workers were first trained by three expert trainers in the coaching program (34 hours). They were then provided with supervision and telephone support when coaching the carers. Coaching was tailored to individual carer needs and abilities, carers were helped to achieve mastery in self-efficacy for caring, and peer support among carers was facilitated.

Carers used semi-structured diaries to record and monitor their short- and long-term goals and help-seeking behaviour with the assistance of their coach. Coaching manuals and carer learning manuals and techniques were developed specifically for the study, and were piloted with five carers of people with Parkinson's disease and cognitive impairment and four carers of people with dementia.

The pilot materials were reviewed and revised by six dementia carers of different cultural backgrounds, five dementia carer support staff and three team members. When requested, Chinese carers with limited English skills were provided with translated carer manuals that were produced by official health translation services, and approved by Chinese bi-lingual staff trainers and consumer group representatives.

By preference, 13 carers received one-on-one coaching by eight trained carer support nurses. Coaching was provided for about one hour each week over 20 weeks in their own homes. It took carers between 20 and 30 hours to complete the seven modules.

While the carer was involved in the one-on-one coaching, their family member with dementia was engaged in an

activity, such as working in the garden, watching television, sorting out their wardrobe, or resting. The 32 carers who wished to access available respite services for the PWD received 20 hours of group coaching by six different carer support nurses and four social workers working in pairs. Between six-12 carers attended one of six groups for 10 coaching sessions of two hours each, totalling 20 hours.

How did we evaluate coaching outcomes?

To evaluate the outcomes of coaching for carers, the project was undertaken in a pre/post/follow-up design using mixed methods over 24 months. Participant recruitment and assessment were undertaken by three trained project staff who were blind to group allocation, and whose inter-rater reliability scores reached 0.89 for all measurements. Participant identities were protected by allocating unique code numbers for all recorded data and using confidential codename lists which were retained by project staff in secure file systems.

Baseline data were obtained prior to carer assignment to individual or group coaching, or to usual dementia support (comparison group). Baseline data included carer demographics – age, gender, English language background, culture, education level, carer status, support from family and friends, total household income (adequate to needs),

and daily consumption of alcohol and medicines.

The coaching program's effectiveness was assessed by a change in scores on the Revised Self-Efficacy Scale (Steffan *et al* 2002) and SF-12 (health) (Ware & Keller 1996). Effect sizes between outcome measures for each of the three groups were analysed according to the instrument developers' guidelines, and 95% confidence intervals (CI) around the mean.

The descriptive statistics included examining the frequency distributions, means and standard deviations. Parametric tests (t-tests) were used for normally distributed data. The percentage changes in Caregiving Hassles Scale (Kinney & Stephens 1989) scores were calculated. De-identified carer goal data, obtained through carer interviews and goal diary entry reviews, were content analysed using Gibbs' (2007) framework.

How did carers benefit?

Of 91 carers enrolled at the beginning, 79 remained two months post-coaching and 63 at four months follow-up. Twelve carers decided to exit the project when the PWD died, or when the PWD moved to an assisted care facility (n=16).

Based on 95% CIs around the Revised Self-Efficacy Scale and SF-12 scores, there were no notable differences between carers who remained in the study and carers who exited,

with the exception of the Vitality domain of the SF-12. Carers had a similarly low mean baseline score of 41.85 (range 40.26-42.21) for Vitality on exiting the study, compared with a mean score of 40.28 for individual coaching and 42.20 for group coaching, and lower than the mean score of 45.83 for the control group.

At baseline PWD had an average age of 82 years (range 54-93), two thirds were male and with moderately impaired cognition, having an average MMSE score of 19.42 (range 14-28), or a RUDAS score of 15.83 (range 5-28). The exiting carers' PWD had reduced cognitive abilities, with an average MMSE score of 17.15, or an average RUDAS score of 14.22.

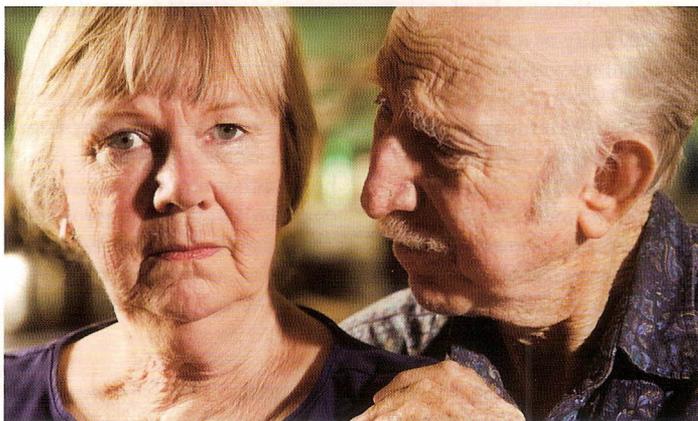
Self-efficacy

(Revised Self-Efficacy Scale)

Across three domains of carer self-efficacy (SE) at baseline the control group reported higher (better) mean self-efficacy scores than both coaching groups for: Seeking Help From Others (62.69 vs 38.44, 40.12); Managing Behaviours (70.62 vs 66.50, 64.23); and Controlling Negative Thoughts Associated with Caring (71.77 vs 60.75, 64.76). Two months after receiving individual and group coaching the carers were more confident in SE for Managing Behaviours (76.83, 75.25) than the control group carers (62.86). Improvement in Controlling Negative Thoughts Associated with Caring also improved for carers receiving coaching (74.50, 78.49), compared with the control group carers (52.57). These improvements continued at four months follow-up for both coaching groups, in contrast to the control group scores which deteriorated.

Health (SF-12)

At baseline all carers' mean health scores for every area of self-rated health were lower than those for Australian adult carer SF-36 normative data (ABS 1995). While associated effect sizes were small at baseline, by follow-up the



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carers receiving individual coaching consistently scored higher than the control group carers for Physical Functioning (84.29), Role Physical (84.29), Bodily Pain (83.29), Vitality (76.2), Social Functioning (89.29), Role Emotional (72.38) and Emotional Health (63.14). Group coached carers reported even higher health improvements from baseline than control group carers, particularly for Role Physical (83.56), Bodily Pain (84.35), General Health (86.36), Social Functioning (90.30) and Role Emotional (71.25).

Caring hassles

(*Caregiving Hassles Scale*)

At baseline most of the carers felt hassled by many aspects of caring, such as managing the PWD's Activities of Living (38.5-75%), diminished Cognitive Status (92-100%) and Behaviour (86.6-93.8%) and in maintaining Social Networks (39.5-56.2%). Being hassled by the PWD's Cognitive Status and Behaviour continued post-coaching and at four months follow-up for 100% of control group carers (n=35, 31).

Eight of 12 carers who received individual coaching were not hassled by Cognitive Status and nine of 12 by Behaviour two months post-coaching. These findings remained for six of seven carers at follow-up. Twenty five of 32 carers receiving group coaching were not hassled by Cognitive Status and 23 of 32 were not hassled by Behaviour. Carer hassles related to maintaining Social Networks reduced for six of 12 individually coached carers and 13 of 32 (39.1%) group coached carers. These reductions continued for 40.9% and 50% of these carers respectively at four months follow-up. In contrast, there was a reduction in Social Networks hassles for only 10 of 35 control group carers at post-test and only three carers at follow-up.

Carer goal achievement

Carer goal achievements varied in scope across all three

groups, but were more positive for the carers who received coaching, with many long and short-term goals being achieved using strategic approaches. Twenty-eight of the 32 carers engaged in group coaching reported success and satisfaction in goal achievement for themselves and the PWD, as a result of sharing ideas with other carers and because of the goal development activities conducted during group learning. In contrast, only six out of 35 control group carers attempted to use their goal diary to identify and achieve self-determined goals.

The following themes were common for all carers receiving coaching:

Enablers and barriers to achieving goals

A strongly-held sense of commitment enabled carers to achieve the goal of maintaining close connection with the PWD, despite continuing deterioration and the difficulties faced each day, which was an important well-being factor. Accepting diminishing capabilities caused by dementia made it less difficult for carers to achieve their goals. These included feeling contented with the difficult caring role, the situation they found themselves in and learning how to remain calm.

By contrast, carers generally expressed feelings of guilt when they decided to prioritise their own needs, mainly because of the weight of responsibility as a sole carer, and if things went wrong for the PWD when accepting help from others. Memory loss and failing concentration were limitations in the PWD that created barriers to the carers' goal of helping them to be more independent. Coming to terms with the PWD's reduced independence in activities of daily living, such as bathing and going to the toilet, was one of the most difficult aspects of the caring role. This issue created barriers for carers in achieving their goals.

Understanding and better managing behaviour

This was achieved by learning to appreciate the person more and understanding how the dementia disease process was affecting the PWD's abilities and behaviours. Since gaining knowledge of how to reduce the stimuli that tended to trigger some behaviour was common for all carers, achieving this goal gave carers a great deal of satisfaction and feelings of well-being.

Seeking support from others

While all carers were offered advice and assistance to access respite care so that they could attend carer support groups, engage with the coaching program and take time out for social activities, initially at least half of all carers elected not to take this opportunity, citing an unwillingness to leave the PWD with "strangers". As well, many carers believed that the PWD "would be upset if they were left in the care of others".

Carers with the goal of learning to seek support from others, including extended family, were happy to find that this support was accepted by the PWD and it helped them to have a more objective approach to their role. Over time, the majority of these carers reported positive effects from setting out strategies to seek support in the caring role. Comparison group carers, on the other hand, continued to express feelings of stress and despondency in regard to gaining support from others.

Feeling more confident in the caring role

Carers reported that focusing on self-determined goals helped them to feel more confident in the caring role. The responses included being able to cope more effectively and to accept guidance in caring.

Engaging in health maintenance

One of the positive effects of goal-focused behaviour and learning to develop self-

efficacy for caring was for carers to focus on their own, as well as the PWD's, health and well-being. Engaging in healthy activities included attending to normal life activities uninterrupted by their caring responsibilities.

Beneficial changes in the caring role

Similar to international study findings, the carers' baseline stress, despondency and exhaustion scores were high, they had low self-efficacy for caring responsibilities and their health and well-being were affected by the caring role. They had lower levels of self-reported health at baseline than Australian carers of adults with intellectual and/or physical disabilities and carers of adults in poor health (ABS 1995).

Carers reported being unable to think about their own needs while concentrating on their immediate and many caring responsibilities. Their focus was on how to cope with new responsibilities that arose for them owing to the PWD's failing abilities and behaviour. Some carers indicated that they did not have the support of family and friends in this role, while others reported their income was insufficient to meet their needs and to pay for community support services, such as respite care.

From these poor baseline scores, after participating in the coaching program the carers' confidence with responding positively to the changed behaviour of the PWD and their feelings of health and well-being surpassed international comparative data (WHO 2010).

Unlike the comparison group, the majority of carers who received coaching were able to frame their caring issues and responsibilities more positively, which suggests that developing self-efficacy for caring can help in taking better control of the complex caring role. Some of the first goals established by carers were associated with paying attention to their own

health concerns, accepting and responding more strategically to dementia symptoms and developing strategies to adapt to the PWD's cognitive decline.

The carers participating in group coaching were more willing than individually-coached carers to seek help for these goals outside of the immediate family by investigating and making use of a wide range of community-based services. This was a positive outcome of coaching, since an issue for respite services and respite referral agencies is to convince carers that having time away from the caring role will ultimately help them to sustain their health and caring abilities over the longer term.

Coaching was a catalyst for having the Chinese carers accept and make use of respite services for the first time. These carers initially expressed reluctance to access respite services because of the cultural stigma associated with having a family member with dementia, the tradition of forbearance when faced with difficult family issues and strong family obligations to care for older members. These strongly-held views were relaxed during the coaching program when Chinese carers accepted that their own health was a paramount factor in their ability to continue in the caring role.

Many of the health-related goals that carers set for themselves were achieved through stress reduction techniques learnt during the coaching program and by giving themselves permission to let go of insoluble issues.

Ongoing benefits for dementia carer support services

One successful aspect of the carer coaching program was that at the end of the project the majority of carers who had received coaching decided to meet regularly with other carers for mutual support and were very satisfied with the coaching support they had received. The majority of carers came to appreciate that caring

responsibilities can be shared with others outside the family without any deleterious effects to the PWD.

An important outcome was the ongoing coaching training being passed on to colleagues by the nurses and social workers who mastered these skills during the project. The carer coaching program has now been embedded in the carer support offered by these services, enabling further skill training for their staff and opportunities for over 400 carers who have subsequently accessed their services. ■

For information on accessing the coaching manuals, carer learning manuals and techniques used in the Carer Coaching Program, email the author at l.chenoweth@unsw.edu.au.

Further information about the program is available on the Dementia Collaborative Research Centres' project page at www.dementiaresearch.org.au/search-results.html?view=dcrc&layout=project&pid=121.

Acknowledgments

The project was funded by two grants from the Dementia Collaborative Research Centre: Assessment and Better Care (DCRC:ABC), UNSW Australia in 2011 and 2013. The project was only possible because of the generous contribution and commitment of the health staff and dementia carers from Alzheimer's Australia NSW, the Dementia Behaviour Management Advisory Services, the Australian Chinese Community Association, the Australian Nursing Home Foundation and the Northern, South Eastern and South Western Sydney Local Health Districts, and the guidance of the study team members Professor Jane Stein-Parbury (University of Technology Sydney), Professor Yun-Hee Jeon (University of Sydney) and Georgene McNeill (Alzheimer's Australia NSW).

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