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## RESEARCH ARTICLE

# Evaluation of an educational program for people with dementia and their caregivers

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**Abstract**

**Objectives:** This study evaluated the impact of a 5-week educational and supportive program for people newly diagnosed with dementia and their caregivers.

**Methods:** The study involved a pretest–posttest survey followed by interviews. Wilcoxon signed-rank test was conducted to determine postprogram changes. Kruskal–Wallis tests measured variation in responses between the people with dementia and their caregivers. Interviews were analysed using the NVivo software identifying themes against the program objectives of improving knowledge on dementia, coping strategies, communication and support services for people with dementia and their caregivers.

**Results:** Fifty-three dyads ( $n = 106$ ) completed the survey. There were significant improvements in participants' level of understanding of dementia ( $z = -8.04$ ,  $p < 0.001$ ), knowledge of local services ( $z = -8.11$ ,  $p < 0.001$ ) and coping with life with dementia ( $z = -6.93$ ,  $p < 0.001$ ). These findings were consistent with interview data from 16 dyads.

**Conclusions:** The increasing number of people with dementia and their caregivers living in the community present health challenges. Programs that assist this group to function well in the community are important. Evaluation of this program indicated improved outcomes in relation to adjusting to life with dementia, enhancing knowledge, fostering communication and reducing feelings of isolation. Areas of improvement included lengthening the program with ongoing contact sessions with program facilitators and other participants. Given the positive effects of the program on this vulnerable group of people, it maybe useful for health-care agencies involved in dementia care to conduct this type of program as a matter of routine treatment and care for people newly diagnosed with dementia.

**KEYWORDS**

caregivers, community health care, dementia, education of patients, program evaluation

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## 1 | INTRODUCTION

Dementia is a major cause of disability, dependency and death, and poses one of the greatest challenges in the 21st century affecting almost 50 million people worldwide, and is expected to increase to 152 million by 2050.<sup>1</sup> The rising number of people with dementia (PwD) places a high financial burden on the health-care system globally with an estimated US\$1 trillion annually, which is projected to double by 2030.<sup>1</sup> In Australia, there are currently 487,500 PwD, with the lifetime cost of care estimated to be more than AU\$15 billion.<sup>2</sup> Over 90% of PwD live in the community and receive care from family members<sup>3</sup> who are critical to their quality of life.<sup>4</sup>

A diagnosis of dementia is devastating for PwD and family members due to the unpredictable nature of the disease, its progression and financial hardship.<sup>5</sup> Family members play an important role in providing PwD support and care and are central to the PwD being able to continue living in their homes.<sup>3</sup> These family caregivers provide intensive and hands-on personal care and spend more hours a week, for a longer period of time, than their formal caregivers, and often become the 'invisible second patients'.<sup>4</sup> The prevalence of negative effects on these informal caregivers is well-documented with high rates of burden,<sup>6</sup> psychological morbidities and depression,<sup>7</sup> frustration and social isolation,<sup>8</sup> loss of sense of self and identity and in some cases deteriorating relationships,<sup>9</sup> physical ill-health and financial hardship.<sup>5</sup> Furthermore, a dementia diagnosis is often linked to social stigma and negative stereotypes.<sup>10</sup> Dementia Australia is the national peak body for people living with all forms of dementia, their families and carers. It provides a large number of resources for people and a telephone helpline service.<sup>3</sup>

Quality education, training and support programs for PwD and their family caregivers<sup>6,7,11,12</sup> are necessary to enable them to maintain independence in the community. This is especially important for people newly diagnosed with dementia. There are a number of systematic reviews published on the efficacy of supportive programs for PwDs and their caregivers, indicating growing research evidence in this area.<sup>13-15</sup> While there are a number of educational programs for PwD<sup>16</sup> and professional dementia caregivers,<sup>17</sup> there remains a paucity of educational programs involving both PwD and their caregivers. Additionally, in Australia, there was only one published article that reported on the results of a quasi-experimental, non-equivalent group pre- and posttest design using a 7-week educational supportive intervention for dyads living with early stage dementia.<sup>18</sup> The quantitative arm of the Stockwell-Smith, et al.'s<sup>18</sup> study revealed no statistical improvements between the control and intervention groups. These findings are contradictory to other studies

### Practice Impact

Dementia causes disability affecting 50 million people worldwide. Education and supportive interventions designed for both people with dementia and their caregivers yields benefits. Health agencies need to routinely provide this early intervention as it is inexpensive and demonstrates everyday health and social benefits for people living with dementia.

that indicate that interventions for PwD and caregivers combined are known to be beneficial for both groups.<sup>14,19</sup> This suggests a need for further evaluation of this type of intervention in order to provide evidence of its strengths and limitations. This study evaluates the effectiveness of an educational and supportive intervention for both PwDs and their caregivers. The information from the study will inform the development of future educational programs that target these dyads.

The aim of this study was to evaluate the impact of a 5-week dyadic educational program for newly diagnosed PwD and their caregivers. The study objectives were to evaluate whether participating in the program improved participants':

- knowledge of dementia;
- reduced feelings of isolation;
- feelings of support;
- communication with others;
- knowledge of coping strategies living with dementia; and
- knowledge of available support services.

It also evaluated participants' opinions on the length of the program, the content and the way in which each session was structured. This paper describes the findings of this program evaluation.

## 2 | METHODS

### 2.1 | Study design

A mixed-method approach was used to evaluate this dyadic educational program. It consisted of a pretest-posttest survey and interviews with PwD and their family caregivers. Participants enrolled in the educational and supportive program were recently diagnosed with dementia, living in the community, were over 65 years, eligible for the Commonwealth Home

Support Program (CHSP) and able to attend the program with a caregiver. The CHSP is a government aged care service that funds services that assists older people to live independently in their homes and communities. The study received approval from the Edith Cowan University's Human Research Ethics Committee (HREC #2019-00702-OCONNELL).

## 2.2 | The program

This educational and supportive program provided PwD and their caregivers with knowledge and skills to enable them to adjust and manage living in the community. The content of the program was informed by the literature and expert opinion. It was developed and conducted by a community-based public organisation that advocates, educates, supports and engages with people living with all types of dementia and their caregivers. The program consisted of a two-hour, face-to-face, weekly sessions conducted over a 5-week period. Using an interactive approach, it provided information on dementia and expected behaviours, management and coping strategies, and home-based assistive technologies, communication and reducing isolation, planning for the future and accessing supportive services. Each session was divided into two parts: the first in which dyads attended together, followed by sessions where PwD and caregivers worked in separate groups with a facilitator. All dyads received an information booklet which they could refer to as required.

## 2.3 | Data collection and analysis

The survey was designed by experts from the organisation who conducted the program. It consisted of 16 questions: four in the preprogram evaluation and an additional 12 in the postevaluation survey. Three questions addressed participants' level of understanding of dementia, their knowledge of available local services and coping with adjusting to life with dementia. Participants completed these three survey questions before and after the program using a 5-point Likert scale from Very Poor to Very Good. Most of the other survey questions were open-ended and related to the appropriateness of the topics covered and suggestions for improving the program.

De-identified pre- and postsurvey data were analysed descriptively. Kruskal–Wallis tests were used to determine whether before and after responses varied between all participants. A nonparametric Wilcoxon signed-rank test was conducted to evaluate whether there were any changes in the level of understanding of dementia, knowledge of

dementia-related local services and coping with adjusting to life with dementia before and after completing the program. This test was carried out to examine the changes for all participants and between-group (PwD vs. caregivers) level. Data were analysed using SPSS for windows V25<sup>20</sup> at the 0.05 alpha level.

## 2.4 | Interviews

Using purposive sampling technique, participants for the interviews were recruited by the research team. One researcher attended a program session in week three of the program and provided a short presentation about the study and responded to any questions. They distributed an information letter outlining the project, an expression of interest form which included participants' contact details and a stamped envelope addressed to the research team. Interested participants were contacted by phone or email. All interviews were arranged at a time and place convenient to the participants. Interviews were conducted with 16 dyads (PwD and their caregivers) at 2 weeks after completing the program and repeated with 11 dyads at 3 months. The interviews explored in-depth information on the strengths and limitations of attending the program and whether it addressed the program objectives. Each interview was conducted first with the couple then individually with each participant to allow independent conversations and responses from PwDs and their caregivers. Interviews were recorded, transcribed in NVivo-XII transcription and de-identified to maintain confidentiality. Interview data were analysed using content analyses procedure. To ensure rigour, three researchers independently identified patterns and codes in the text. Any disagreements were assessed, and final codes were determined through discussion.<sup>21</sup> Responses were categorised under the six objectives of the program.

## 3 | RESULTS

### 3.1 | Survey

A total of 106 participants (53 dyads) who attended the program between April 2020 and May 2021 completed the survey. Of these, 51 (48%) were PwD, 47 (44%) were caregivers and eight (8%) unknown. After attending the program, percentage of participants with 'good' understanding of dementia increased from 22% to 88%; 'good' knowledge of available services increased from 15% to 88%; and 'coping with life with dementia' increased from 15% to 79%. The majority of participants (80%) found both the whole and split group sessions useful.

Participants were also asked to indicate the program topics they found useful. They could select more than one topic (Figure 1). About two-thirds of the participants (65%) found 'information about other services' the most useful topic. The lowest-rated topics were 'current research' and 'dementia medication' (27% each), and 'obtaining a diagnosis' (25%).

Kruskal–Wallis test indicated no significant differences between the PwD and their caregivers' responses both before and after program completion (Table 1). Therefore, all participants were treated as one group, and their pre- and posttests were compared using Wilcoxon signed-rank test.

### 3.2 | Participants' level of understanding, knowledge and coping pre- and postprogram

Wilcoxon signed-rank test revealed that the participants' level of understanding of dementia ( $z = -8.04, p < 0.001$ ), knowledge of local services ( $z = -8.11, p < 0.001$ ) and coping with adjusting to life with dementia ( $z = -6.93, p < 0.001$ ) improved significantly after completion of the program (Table 2).

Further tests revealed that the improvements were significant with both the PwD and the caregivers, when analysed as separate groups (Tables 3 and 4).

### 3.3 | Interview findings

Participants voiced concerns that the diagnosis of dementia was 'confronting' and a 'shock like being hit by a bombshell' (PwD). Initially, the uncertainty surrounding the lack of knowledge about dementia confronted some participants:

... At first, I really thought I'm going to top myself. I thought I can't live with it because you have this huge idea that everybody's going to want to be away from you in case it's catching [infectious] sort of thing.

(PwD, 11)

### 3.4 | Objective 1: Improved knowledge of dementia

Overall, both the PwD and their caregivers found the program helpful. They found the information enhanced their understanding of dementia and ways in which to manage and cope with everyday living:

It's definitely expanded my understanding ... one of things that you had to do like the guardianship and the self-directives getting the "Will" sorted out properly.

(Caregiver, 11)

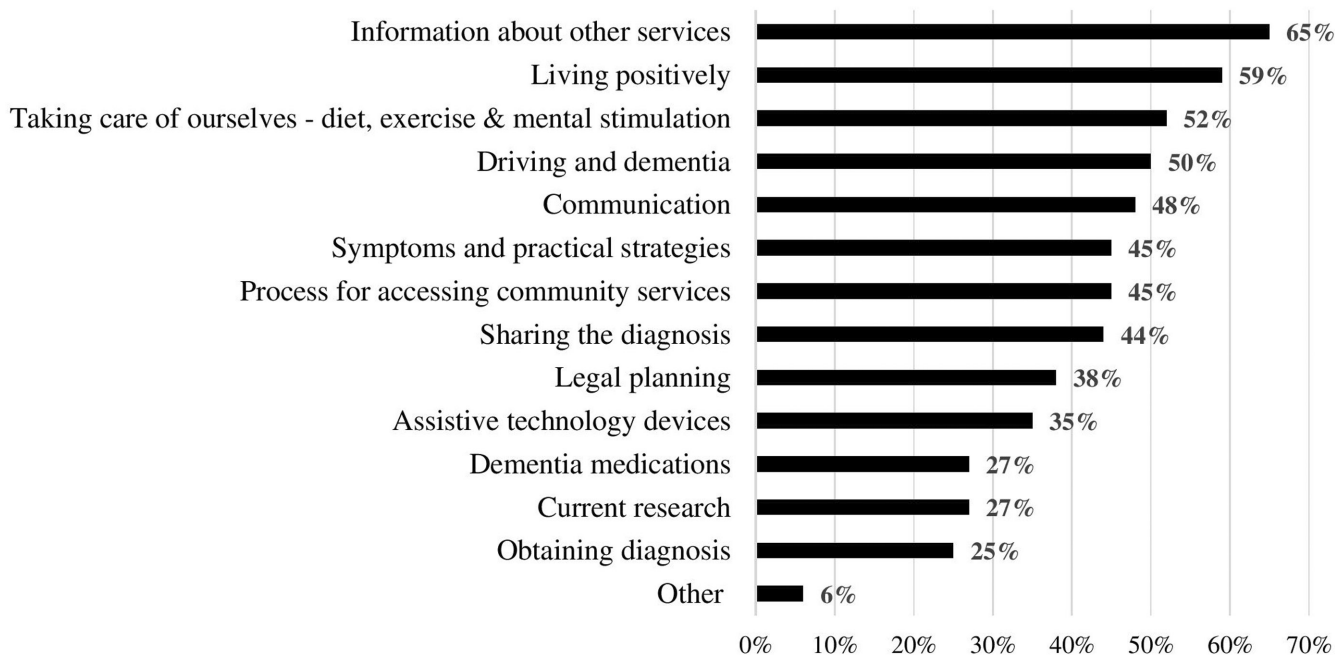


FIGURE 1 Program contents found most useful by percentage of participants (multiple choice)

**TABLE 1** Comparison of level of understanding, knowledge and coping pre- and postprogram between person/people with dementia and caregivers

Survey items	Mean rank		KW test ( $\chi^2$ )	df	Sig
	PwD	Caregivers			
Preunderstanding of dementia	46.95	52.27	0.98	1	0.32
Postunderstanding of dementia	46.32	49.79	0.52	1	0.47
Preknowledge of available services	49.30	49.71	0.01	1	0.94
Postknowledge of available services	45.31	49.89	0.79	1	0.37
Precoping with life with dementia	49.06	47.87	0.06	1	0.80
Postcoping with life with dementia	49.41	44.43	1.11	1	0.29

Abbreviations: KW test, Kruskal–Wallis test; PwD, person/people with dementia.

**TABLE 2** Level of understanding, knowledge and coping pre- and postprogram for all participants

	n	Median	95% CI		z	Sig	r
			Lower	Upper			
Understanding of dementia <sup>a</sup>							
Pre	100	3	1	1.5	−8.04	<0.001*	−0.80
Post		4					
Knowledge of services <sup>b</sup>							
Pre	99	2	1.5	2	−8.11	<0.001*	−0.82
Post		4					
Coping with adjusting to life with dementia <sup>c</sup>							
Pre	98	3	1	1	−6.93	<0.001*	−0.70
Post		4					

<sup>a</sup>Missing n = 4.

<sup>b</sup>Missing n = 5.

<sup>c</sup>Missing n = 6.

\*Significant association at 5% level of significance (2-tailed).

Some participants who had less understanding of dementia and an incorrect attitude towards it found it changed their attitude after attending the program as they realised the seriousness of this condition:

I think [I had] very poor understanding [of dementia]. I think the worse thing, the biggest change for me was realising that dementia's not a comical thing and that it's a tragedy ... I don't know really ... what the future holds, [but] it definitely has helped me.

(Caregiver, 06)

At the 3-month follow-up, participants still commented that the program was helpful and informative, and they would recommend the program to other people in a similar situation:

Well, I think subconsciously we are using it [the information] without sort of thinking too much about it. I'm trying to be more patient [with the PwD] and everything.

(Caregiver, 02)

### 3.5 | Objective 2: Reduced feelings of isolation

Most of the participants said they were not feeling isolated as they were still socialising with their friends and participating with recreational groups and social networks. However, meeting other people undergoing similar circumstances made them feel less isolated:

It was good to listen to other people's problems, how they managed and everything and



TABLE 3 Level of understanding, knowledge and coping pre- and postprogram for person/people with dementia

	<i>n</i>	Median	95% CI		<i>z</i>	Sig	<i>r</i>
			Lower	Upper			
Understanding of dementia <sup>a</sup>							
Pre	49	3	1	1.5	−5.76	<0.001*	−0.58
Post		4					
Knowledge of services <sup>b</sup>							
Pre	49	2	1	2	−5.60	<0.001*	−0.56
Post		4					
Coping with adjusting to life with dementia <sup>c</sup>							
Pre	48	3	0.5	1.5	−4.89	<0.001*	−0.49
Post		4					

<sup>a</sup>Missing *n* = 4.<sup>b</sup>Missing *n* = 5.<sup>c</sup>Missing *n* = 6.

\*Significant association at 5% level of significance (2-tailed).

TABLE 4 Level of understanding, knowledge and coping pre- and postprogram for the caregivers

	<i>n</i>	Median	95% CI		<i>z</i>	Sig	<i>r</i>
			Lower	Upper			
Understanding of dementia <sup>a</sup>							
Pre	46	3	1	1.5	−5.42	<0.001*	−0.54
Post		4					
Knowledge of services <sup>b</sup>							
Pre	45	2	1.5	2	−5.69	<0.001*	−0.57
Post		4					
Coping with adjusting to life with dementia <sup>c</sup>							
Pre	45	3	0.5	1	−4.79	<0.001*	−0.49
Post		4					

<sup>a</sup>Missing *n* = 4.<sup>b</sup>Missing *n* = 5.<sup>c</sup>Missing *n* = 6.

\*Significant association at 5% level of significance (2-tailed).

you know you don't feel quite alone, ... talk to other people who are going through the same thing.

(Caregiver, 02)

shared, or some specific aspect of the course can be re-presented. I've definitely forgotten heaps of that stuff.

(Caregiver, 06)

At the 3-month follow-up, some caregivers thought it would be good to have follow-up sessions on an ongoing basis:

I found that course so revitalising... to have some regular, not just one-off, follow-up. Every three or four months just to get together... Some kind of social, socialising on a regular basis, maybe new information can be

### 3.6 | Objective 3: Improved feelings of support

In terms of feeling supported, participants found being introduced to other people in the program, experiencing the same diagnosis and lifestyle changes very reassuring as it made them realise that they were not alone:

... [I'm] glad, there is other people in the same position but it's nice to know, that you're not on your own, and things like that because it's bad for the person that's got it like me. ...

(PwD, 10)

The caregiver participants felt that the focus of the program was on managing the PwD, and not so much on caregiver support needs. They stated that they would have liked more information on helping them manage their own well-being:

There wasn't a lot about carers, no it was all about the disease and the person ... I didn't feel that there was any, any comfort to the carers except to tell you where you could take the PwD.

(Caregiver, 08)

At the 3-month follow-up, caregivers continued to comment on the need to be provided with more initial and ongoing support as some experienced difficulties managing the changes with the PwD. They also expressed a keenness to keep in touch with other people in their program:

... I felt that the carers need a bit more help, you know, maybe the course could have gone on for another couple of weeks and concentrated on the carers, you know, and the ladies that were with me, like I said, they were all feeling exactly the same.

(Caregiver, 05)

### 3.7 | Objective 4: Improved communication with other people

The PwD and their caregivers found it helpful to share their feelings with other friends:

Yes, I just find it helpful telling friends you know, and knowing that they don't see me any differently.

(PwD, 06)

However, other caregivers found it difficult to talk about their partner's condition or their feelings with other people outside of the program. Yet, they thought that the program changed their views about telling others about their partner's dementia and their situation:

I would find it difficult to talk to [others] I've got one male friend out of my other male friends that I'll talk to. I won't talk to other friends about it and there some that I categorially have not even told that [my wife] has dementia.

(Caregiver, 06)

At the 3-month follow-up, when asked whether the program assisted them to communicate with other people about the PwD's condition, caregivers provided positive responses:

I think ... doing the course taught me that it's not a stigma or, you know, like you can talk about it.

(Caregiver, 04)

### 3.8 | Objective 5: Improved knowledge of coping strategies living with dementia

Overall, participants found the information and strategies from the program assisted them to cope with dementia and the changed behaviours they were managing:

It teaches you to realise there's a [PwD] and a carer and a lot of their stuff to me was aimed at the PwD that sort of was looking after him ... like the cupboards ... [in] a kitchen ... there was little yellow tags everywhere, everywhere, spoons, forks, saucers, cups, fridge ... for somebody that's trying to manage by themselves. .... They showed you on the second lesson all sorts of things like putting a thing on your car keys and having bits of ribbon and having something that beeps and all that ... you can learn from it.

(Caregiver, 08)

After attending the program, some participants felt more prepared for the future:

Oh, definitely yeah, I'm ready for the future, so whatever the future might bring, so with the information come out of the course, I feel a lot more confident that I'll be able to cope when it gets a lot worse.

(Caregiver, 11)

At the 3-month follow-up, participants continued to use strategies to help them manage the dementia symptoms:



... Having a white board, that's in place. Using "Find my phone", I haven't got her a GPS bracelet yet. ... So, I've implemented a fair number of strategies and there are more there.

(Caregiver, 06)

### 3.9 | Objective 6: Improved knowledge of available local support services

The participants indicated that the program increased their knowledge and awareness of the local services available and provided them with information on how to access those services when they needed them:

There was lots of [services] ...I've not heard of before so, as the need arises, we will go through and see what might be appropriate for us.

(Caregiver, 12)

At the 3-month follow-up, participants found it useful and comforting being given information of other services available in the community to help them in the long term:

Definitely the [program] made me feel more relaxed that there were avenues that I could follow, that there were people [support services] I could speak to ...that I wasn't alone.

(PWD, 06)

Some caregivers, with limited knowledge of computer and information technologies, felt the program only provided online information for the local services which they found daunting:

...You have to keep going on-line and probably it's an age thing. it's daunting. If you could just phone up and speak to somebody ... I can't download the form because now we're not using the computer anymore. So, I've got an iPad but I can't download the form, so I've got to send it to my daughter to download.

(Caregiver, 03)

In summary, participants commented that attending the program increased their knowledge of dementia and available support services. They enjoyed the social aspect of meeting other people in similar situations. They also enjoyed hearing others' stories about their experiences

and how they managed everyday situations. They found this comforting and helped reduce their feelings of isolation. Some participants who found it difficult to socialise and talk about their feelings, found that the program made them aware of the need to communicate and socialise with others. Participants requested longer and more follow-up sessions on an ongoing basis. They also requested a need for more sessions and content that focussed on caregiver needs to help them manage their own well-being.

## 4 | DISCUSSION

The quantitative and qualitative arms of the study highlighted many supportive aspects of this program. This evaluation was conducted using measures that were designed by the organisation conducting the program. Although it was developed based on the literature and subject experts, the research team acknowledge the inherent limitations. Future evaluative studies should use more psychometrically established measures and include more demographic data so we can compare group characteristics with study outcomes. This would strengthen the study. Also, it would be beneficial to include a control group as comparison and match the pre- and postsurvey data. All these limitations are acknowledged.

Overall, the participants appraised the program very positively as it alleviated their concerns and provided them with knowledge and skills to manage everyday living. The program also introduced them to other people in similar circumstances, which reduced their sense of isolation. These positive effects are of note as they highlight the benefits of this type of program in providing the dyads with support to adjust and transition into their new roles and an uncertain future.<sup>22,23</sup> The Australian Government has been investing significantly in dementia research over recent years.<sup>2</sup> However, there is limited research in the area of early intervention for PwD and their caregivers, and the pivotal role of education and support interventions to assist them to manage the multiple transitions<sup>24</sup> and improve their physical and cognitive function, and quality of life.<sup>25</sup>

This evaluation indicates the benefits of early education interventions involving both the PwD and their caregiver. Important issues include navigating and managing significant changes in relation to communication, behaviour, safety, and physical and psychological health. Furthermore, caregivers should be supported to ensure they maintain their own well-being. Previous research has illustrated how provision of dementia education can reduce caregiver symptoms of depression and burden.<sup>26</sup>

Studies reveal that three of four caregivers of PwD underutilise available supports and resources,<sup>27</sup> due, in part, to lack of knowledge about available services.<sup>28</sup> The current intervention successfully informed PwD and caregivers of the plethora of available resources and providing a hardcopy resource for future needs. This study highlighted the potential value of a dyadic educational and psychosocial program aimed at successful adjustment and transition, postdementia diagnosis. This intervention showed a significant improvement in the participants' feelings of being able to manage living with dementia, as well as feeling understood and connected to others in the same situation. These results were in keeping with a recent systematic review of dyadic psychosocial interventions, with family caregivers reporting greater connectedness, feeling more useful and viewing caring as being more worthwhile postintervention.<sup>29</sup>

## 5 | CONCLUSIONS

The increasing number of people with dementia and their caregivers living in the community present health challenges. Programs that assist this group to function well in the community are important. Education and supportive interventions designed for both people with dementia and their caregivers yield benefits. Another important factor is the social aspect and the group dynamic that fostered connection and a sense of community. This reduced feelings of isolation among both groups. Health agencies need to routinely provide this early intervention as it is inexpensive and reveals positive health and social benefits for vulnerable people living with dementia.

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## CONFLICTS OF INTEREST

No conflicts of interest declared.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

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