

National dementia supporter programme in Japan

Yoko Aihara  and Kiyoshi Maeda

Kobe Gakuin University, Hyogo, Japan

Dementia
2021, Vol. 20(5) 1723–1728
© The Author(s) 2020



Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/1471301220967570

journals.sagepub.com/home/dem



Abstract

Due to the growing number of people with dementia worldwide, the role of dementia supporters is becoming increasingly important. In 2005, a national campaign called the Dementia Supporter Caravan was launched in Japan. However, the impact these trainings have on facilitating the work of dementia supporters is not quite understood. This study aimed to assess the challenges faced by dementia supporters in conducting activities for people with dementia. Our results showed that even after a period of six months since the training session, only half of the supporters had commenced new support activities. Future studies should examine the impact activities conducted by dementia supporters have on people with dementia and their family caregivers.

Keywords

dementia supporter, dementia-friendly community, social activities, training programme, public awareness

Introduction

Although the number of people with dementia is growing worldwide, dementia-support services are facing substantial challenges, including low public awareness ([World Health Organization, 2015](#)). For people with dementia and their families, lack of awareness as well as the general public's poor understanding of dementia may represent a barrier in seeking help from members of their local community. Dementia awareness and friendliness are one of the global action plans, and the World Health Organization recommends that every member states should have at least one functioning public awareness campaign on dementia to foster a dementia inclusive society by 2025 ([World Health Organization, 2017](#)). Japan has the highest ageing rate in the world, and to support increasing number of people with dementia, campaigns to raise public awareness of dementia and building dementia-friendly communities were launched well in advance. In 2005, the Japanese government pioneered a new community support system for people with dementia and their carers called the

Corresponding author:

Yoko Aihara, Kobe Gakuin University, 518 Arise Ikawadani-cho Nishi-ku, Kobe-City 651-2180, Hyogo, Japan.

Email: yanzu99@gmail.com

‘Japan National Campaign of Dementia Supporter Caravan (*Ninchishou supporters*)’, which also helped in raising public awareness on dementia (OECD, 2015). Similar programmes have since been adopted by other countries that are generally labelled as ‘dementia friend’ programme. As a result of the implementation of this programme in Japan, by the end of 2018, over 10 million dementia supporters had been trained in the country. Specifically, the design of this national dementia strategic plan involves one individual educating a group of dementia supporters, who then support people with dementia in their own communities. In previous research, a follow-up study was conducted on the effects of this programme, and it was found that participants’ attitudes towards people with dementia improved after attending a training session (Kim and Kuroda, 2011). However, the efficacy of the programme in terms of promoting action among the dementia supporters it trains remains unclear. Furthermore, to our knowledge, the various barriers faced by dementia supporters when providing support activities have not been well monitored or evaluated in previous studies. Consequently, this observational study aimed to examine the challenges dementia supporters face while promoting support activities for people with dementia.

Dementia supporter training programme

The dementia supporter training programme involves one session of a 60–90 minute face-to-face class instructed by a ‘dementia caravan mate’, who has completed a six-hour training course. Using a textbook and a digital versatile disc, the training programme provides information on the types and symptoms of dementia and the means for effectively supporting people with dementia. At the end of the session, dementia supporters receive orange bracelets as a form of certification.

Methods

Study setting and subjects

In this study, we surveyed participants of a dementia supporter training session in Kobe City, Japan. Kobe is one of the government-designated cities comprising a population of approximately 1.5 million with an ageing rate of 27.1% (national average of ageing rate 27.7%) as of 2016. The sample size was calculated as 10% of the sampling error, and the effect size of the session was 60% with 95% confidence interval. Therefore, the desired sample size was 96 participants.

We organized dementia supporter training programmes and the two training programmes were conducted on different days. A structured questionnaire was administered to 111 community-dwellers who had attended the training programmes. A questionnaire was distributed at the end of the sessions, and 66 attendees filled the questionnaire (response rate = 60%). Furthermore, six months after the training session, a follow-up survey was conducted, and the questionnaire was distributed to 66 supporters who had completed the initial survey. Among them, 43 supporters responded (response rate = 65%). Therefore, we analysed 43 respondents who completed the initial and follow-up questionnaires.

Variables

Since the dementia supporter training programme aims to raise public awareness and understanding of dementia and promote dementia-friendly communities, the study assessed the dementia supporters’ knowledge of dementia and their intention to support people with dementia. The initial survey obtained the participants’ characteristics (age, gender and occupation), experience of

interacting with people with dementia, knowledge of dementia and frequency of obtaining information on or having conversations about dementia. To determine the participants' knowledge of dementia, 15 questions developed by Kim et al. (2011) were used, with possible responses being 'true', 'false' or 'do not know'; Cronbach's alpha for the knowledge items was 0.72, demonstrating moderate internal consistency.

In the follow-up survey, the participants were asked about self-efficacy as dementia supporters and the types of dementia-related activities they conducted. The self-efficacy questions were constructed based on the government's expectations of dementia supporters: (1) have an accurate understanding of dementia, (2) act in an unprejudiced manner towards people with dementia, (3) show compassion towards people with dementia and their families, (4) support people with dementia and their families, in the community as much as individually possible, (5) identify activities that can support people with dementia in the community and (6) invite friends and family members to participate in support activities for people with dementia. The participants' self-efficacy as dementia supporters was assessed by determining their level of confidence regarding fulfilling these six questions. These questions were marked using a four-point scale, where '3' meant 'strongly agree', '2' meant 'agree', '1' meant 'disagree' and '0' meant 'strongly disagree'. Self-efficacy was calculated for the six roles (ranging from 0 to 18 points), with a higher score indicating higher self-efficacy. Further, the participants were asked about the type of activities they conducted and if they commenced new support activities after attending the training session.

Analysis

Descriptive statistics were used to assess the data. The outcome variables were self-efficacy of dementia supporters and initiated supporters' activities six months after the training session. Univariate linear regression model was used to examine the associated factors of self-efficacy of dementia supporters. Univariate logistic regression model was used to examine the associated factors with the initiation of dementia supporters' activities. The explanatory variables were characteristics of participants, experience of interacting with people with dementia, frequency of participating in training sessions and knowledge of dementia. All statistical analyses were conducted using Stata 14.0 (Stata Corp, TX, USA), and the statistical significance level was set at $p < 0.05$.

Ethics

All participants were briefed about the study protocol in both verbal and written forms. Ethical approval for this study protocol was granted by the Ethical Committee of the Kobe City College of Nursing (protocol number 2015-1-28, approved data on March 16, 2016).

Results

Subject characteristics

The mean age of the participants was 62 years (ranging from 21 to 80 years). Further, 74% of the participants were women, and 67% of the participants had retired or had no job. Approximately 14% of the participants had attended dementia supporter training sessions more than twice. Additionally, approximately 76% of the participants had previous experience in interacting with people with dementia. Major reasons for attending the training were 'useful for own self' (77%) and 'useful when needed care for family' (58%).

Factors associated with self-efficacy

Almost 40% of the participants stated that they had sufficient confidence in their ability to ‘act in an unprejudiced manner towards people with dementia’ and ‘compassionately support people with dementia’. However, approximately half of the participants did not have confidence in their ability to ‘identify support activities for people with dementia’ or ‘invite family and friends to engage in support activities for people with dementia’.

Univariate linear regression showed that the participants who had attended dementia supporter training sessions more than twice, had experience in interacting with people with dementia, had greater knowledge of dementia had higher self-efficacy as dementia supporters than those who had only attended training sessions once, had no interactive experience with people with dementia and had lower dementia knowledge (Table 1).

Factors associated with engaging in support activities

The follow-up study showed that during the six months after the dementia supporter training session, 20 participants had commenced new support activities for people with dementia. Furthermore, 12 participants answered that they wore orange bracelets for easy identification as dementia supporters for people with dementia and their family members, and nine participants had begun volunteer activities. Univariate logistic regression showed that those who had experience interacting with people with dementia were more likely to commence support activities after the training session than those who had no interactive experience with people with dementia (odds ratio = 12.2, 95% confidence interval = 1.38–107.87).

Discussion

Although the government expects that, through the sessions, dementia supporters independently learn about the efforts they can make to support people with dementia, this study found that six months after the training session, only half of the participants had initiated support activities. Further, we also found that previous experience interacting with people with dementia and higher knowledge of dementia are positively associated with greater self-efficacy in terms of being a dementia supporter and exhibiting helping behaviour. This result was somewhat expected as, even among health professionals, attitude towards dementia varies depending on individual experience, knowledge and skills (World Health Organization, 2012). Furthermore, although the training session

Table 1. Univariate linear regression analysis for factors associated with self-efficacy of dementia supporters.

Variable	Coefficient (SE)	p-value
Age	−0.03 (0.04)	0.40
Gender (ref. men)	0.19 (1.06)	0.86
Job (ref. working)		
Not working	0.89 (0.98)	0.37
Number of times attended training session (ref. first time)	2.81 (1.26)	0.03
Experience in interacting with people with dementia (ref. never)	2.88 (1.00)	0.006
Knowledge scores of dementia	0.50 (0.18)	0.009
Frequency of gathering information and conversation about dementia	0.75 (0.48)	0.12

SE: standard error; ref.: reference.

taught dementia supporters how to engage with people with dementia, our results suggested that without experience in interacting with people with dementia, supporters had difficulty devising methods to support people with dementia in the real world. A possible means of addressing this issue has been highlighted in a previous study; research suggests that creating continuing opportunities to learn more about dementia and collaborating with professionals are motivating factors in this regard (Söderhamn et al., 2012). In other words, providing additional training sessions, seminars and information regarding dementia can maintain supporters' motivation to help people with dementia.

Another study showed that only 0.1% of the people with dementia in Japan requested assistance in the form of informal care from dementia supporters (Itou et al., 2014). Unfortunately, the societal recognition of the role of dementia supporters remains poor. Similar findings have been reported regarding community health volunteers; for example, although the community health volunteer programmes have been internationally acclaimed as a model programme, they lack community recognition and professional respect (Schwarz et al., 2014). Even though several trained dementia supporters have fulfilled the goals set in the national policy, further advocacy efforts are required to raise awareness about the role of dementia supporters.

Despite the several issues found regarding raising awareness on dementia through National Dementia Supporter Caravan, this study has several limitations. The sample size of the survey was small ($n = 43$), and the study was conducted in urban communities; therefore, the results cannot be generalised to all of Japan, particularly because social networks differ between urban and rural communities.

Conclusion

This study suggests that dementia supporter training sessions provide an opportunity for the general public to increase their awareness about dementia. Majority of the people with dementia live in their own communities as well as in Japan. Thus, the role of dementia supporters is becoming increasingly important for promoting dementia-friendly communities. To encourage dementia-friendly attitudes in the community, evidence-based interventions should be examined, as this would facilitate in sharing experiences of different countries.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: The study was supported by 2016 Joint Research Grant Programme of the Centre of Community, Kobe City College of Nursing.

ORCID iD

Yoko Aihara  <https://orcid.org/0000-0003-1371-2501>

References

- Itou, M., Suzuki, R., & Itou, D. (2014). Types of functions of informal support used by people with dementia: Suggestions for dementia care management. *Journal of Japanese Society for Dementia Care*, 12(4), 731-741 (in Japanese).

- Kim, K., & Kuroda, K. (2011). Factors related to attitudes towards people with dementia: Development attitudes toward dementia scale and dementia knowledge scale. *Bulletin of Social Medicine*, 28(1), 43-55 (in Japanese).
- Kim, K., Zhen, X., Masui, K., & Kuroda, K. (2011). A follow-up survey to perception of dementia among trained dementia supporters. *Journal of Japan Dementia Care Association*, 10(1), 88-96 (in Japanese).
- OECD. (2015). *Addressing dementia: The OECD response, OECD health policy studies*. OECD Publishing. DOI: [10.1787/9789264231726-en](https://doi.org/10.1787/9789264231726-en)
- Schwarz, D., Sharma, R., Bashyal, C., Schwarz, R., Baruwal, A., Karelas, G., Basnet, B., Khadka, N., Brady, J., Silver, Z., Mukherjee, J., Andrews, J., & Maru, D. S. R. (2014). Strengthening Nepal's female community health volunteer network: A qualitative study of experiences at two years. *BMC Health Services Research* 14(1), 1-6.
- Söderhamn, O., Söderhamn, U., Landmark, L., Aasgaard, H., Eide, H. (2012). Volunteering in dementia care – a Norwegian phenomenological study. *Journal of Multidisciplinary Healthcare* 5, 61-67.
- World Health Organization. (2012). *Dementia: A public health priority*: World Health Organization.
- World Health Organization. (2015). *First WHO ministerial conference on global action against dementia: Meeting report*. World Health Organization.
- World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. World Health Organization.

Yoko Aihara, PhD, is a registered nurse, public health nurse and associate professor in the Kobe Gakuin University, Japan. Her research focuses on active ageing and health promotion for older adults. She is interested in the development of education programme for dementia befriends in Japan.

Kiyoshi Maeda, PhD, is a medical doctor specialized in geriatric psychiatry and a professor in the Kobe Gakuin University, Japan. He is also a supervisor of dementia policy in Kobe City, Japan.