The Effects of Training Workshop for Cognitively Intact Community Dwelling Older People on Knowledge of Dementia and Dementia Worry in Hong Kong

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Abstract

Background: Dementia is a global challenge. Little is known about the cognitively intact older people regarding their knowledge and worries about dementia. The aim of the current study is to assess the effects of training workshop to these group of people on the knowledge and their worries about this disease.

Methods: An interventional study with convenience sampling technique was conducted. Eligible older people who were residing in community and were cognitively intact were invited. A 3-hour workshop was given. Their knowledge was assessed by the Chinese version of the Alzheimer's Disease Knowledge Scale (ADKS). Their worries were assessed by the Modified Dementia Worries Scale (MDWS). Questionnaires were given to them before and after the training workshop.

Results: Among the 177 recruited subjects, 149 participants successfully completed the pre and post questionnaires. The score of ADKS was slightly above average before the training and most of the participants were not too worried about the disease. There was a significant increase in the ADKS and decrease in MDWS after the training.

Conclusions: The cognitively intact older people in the community demonstrated a very general knowledge on dementia with some knowledge deficits, they were not too worried about this disease. Training help to strengthen their knowledge and correct their misunderstandings. The result suggests more trainings should be provided to fill the knowledge gap. When more people have better understanding to this disease, it may lessen unnecessary worries and improve their quality of life.

Keywords: Community, Older People, Cognitively Intact, Dementia, Knowledge, Worry

Introduction

Dementia is a progressive degenerative brain disease characterized by several symptoms that impair the cognitive, behavioral and physical functions. There are six common types of dementia, namely Alzheimer's disease (AD), vascular dementia, Lewy body dementia, fronto-temporal dementia, mixed dementia and dementia with reversible causes in which Alzheimer's disease is the most common cause of dementia, accounting for 60 to 80 percent of cases (Centers for Disease Control and Prevention (CDC, 2019). The early sign of dementia, just like forgetfulness is often overlooked, and till later stage, the demented client becomes more physically dependent with very significant memory loss.

According to World Health Organization (WHO, 2021), the number of people living with dementia worldwide is currently estimated at over 50 million in 2021 and will almost triple by the year 2050. There are nearly 10 million new cases annually. The total number of people with dementia is projected to reach 82 million in 2030 and 152 in 2050 (WHO, 2020).

All these figures are scaring as dementia does not only affect those suffering from this disease, it also poses great caring burden to their families and caregivers, they need to care for their personal and physical needs, as well as to manage their behavioural and psychological changes. Dementia also exerts great social and economic burden in global aspect. Its economic cost included direct costs, such as special nursing care, home healthcare, and long-term care, and indirect costs, such as quality of life and the impact on the caregiver. In 2015, the total global societal cost of dementia was estimated to be US$ 818 billion, equivalent to 1.1% of global gross domestic product (GDP) (WHO, 2021).

Despite the number of dementia is increasing globally, there are still a lot of myths regarding this disease. People often thinks dementia is similar to forgetfulness and is common in older people, also they thought brain cells are lost each day, and when people get old, the brain cells will run out ultimately (Dementia Australia, 2020). Some thinks that dementia only attacks older people, and it won't be fatal. All these are the myths about dementia and trigger unnecessary worries especially to the older generation.

Older people generated higher levels of fear of getting demented than any other disease, as dementia cannot be healed, and no medication can fully slow down the deterioration. Studies showed that the fear of getting dementia was as great as the fear of getting cancer. Data from different countries, such as England showed that two-thirds of the subjects over 50 years of old feared they would develop dementia compared with only 10% of fear of getting cancer. In France, 47 % of people over 60 years reported dementia was the disease that they most fear of. Thirty-one percent of Americans aged over 55 indicated that it was the disease they most fear of. Among aged 55 and above, they worried about getting dementia especially those with first degree relative with confirmed dementia (Cutler and Bragaru, 2015). Norman (2020) reported that for cognitively intact older people, nearly half of the participants reported that they were very concerned about getting dementia and approximately 16% reported being very concerned. Although majority of the studies showed older people worried about getting this disease, some studies showed only 29.4% of people expressed worry (Roberts, McLaughlin and Connell, 2014) and in the study by Horan, Jones, Pendleton (2007), 69% of the older people did not worry about getting demented. Williams, Tappen, Rosselli, Keane, Newlin (2010) indicated that participants with the experience of having demented relatives might increase their awareness and concern.

One of the reasons that older people worry about getting dementia was because of the lack of knowledge of this disease (Kim, Sargent-Cox and Anstrey, 2015). In Liu et al (2019), the knowledge score about dementia in China was only 63.14%, with only half of the participants could identify the risk factors correctly. Chinese people have low level of knowledge about dementia was mainly aged over 60 years old, with low education, live in rural areas and exposure to information on dementia. Scerri and Scerri (2017) reported that different educational programmes were organized for formal and informal caregivers but seldom emphasis on cognitively intact older people. Training of these group of people is important and may improve their knowledge of the disease. The study also showed that the introduction of such training programmes on dementia for older people may lead to healthier lifestyle behaviours, more help-seeking behaviours and is able to correct their misconceptions about this disease. Dementia is often scaring not only to people having the diagnosis, but also to older people who is still cognitively intact and physically healthy. The lack of correct concept and understanding resulted in stigmatization and barriers to diagnosis and care (WHO, 2020).

The picture of the number of dementia cases in Hong Kong is similar. The prevalence rates of dementia in Hong Kong is estimated to be at 5%-8% in older people aged over 65, and at 20%-30% among those aged over 80. Also, for people aged 60 and above, it is estimated to have around 333, 000 suffering from dementia and there will be 11% of people having dementia in 2039 (Yu, 2012). Lam et al (2019) had conducted a study on the perceptions of Chinese towards dementia in Hong Kong, the fear of dementia was found to increase with increasing age. Lack of knowledge is one of the main reasons. There is quite a few health educational programmes organized for healthcare workers, caregivers, domestic helpers about caring for dementia clients, however, for those cognitively sound older adults, they fear of having dementia and trigger a lot of worries, not many training programmes tailored made for them. If they do not equip with correct concepts and better understanding about this disease, unnecessary worries and fears will exist, as a result, the quality of life decreases, therefore early training and health education are of urgent needs. In view of this, it is worthwhile to explore the effects of training workshop to cognitively intact older people about their knowledge and worry of getting this disease, so that further implications may be tailormade for them to increase their dementia knowledge, alleviate their worries, improve their quality of life and lead a healthier lifestyle.

Materials And Methods

Research plan and methodology

This was an interventional study with convenience sampling technique. Eligible older people who were residing in community and were cognitively intact were invited.
A 3-hour workshop was given. The content of the workshop included:

- Understand basic concept and stages of dementia.
- The physical and psychological symptoms of dementia.
- Care of dementia clients in activities of daily living.
- Communication skills with demented clients.
- Community support for demented clients and the caregivers.

Questionnaires regarding knowledge of dementia and dementia worry were given to them before and after the training workshop.

Sampling

Cognitive-intact community dwelling older people from community elderly centres of the non-governmental organizations were invited. The cognitive state of all potential participants was assessed by the Abbreviated Mental Test (AMT) for Chinese population. The inclusion criteria of the study were older people aged 65 or above, cognitively intact, with AMT score 6 or above, able to communicate in Cantonese, capable of providing informed consent. For those participants that had difficulties in reading, the investigator would help to administer the questionnaires.

Recruitment

The researcher contacted the directors and supervisors of the community centres, then visited those homes to ensure the venues were able to conduct the training workshop, also discussed with them the programme details.

Sample Size Calculation

Previous research indicated that a minimal sample size of 156 subjects were needed for the study of power 0.8, alpha 0.05, assuming small effect size of 0.2.

Procedure

Eligible subjects from the community centres were recruited and assessed. Initial screening assessment using AMT was done by the research assistant before the commencement of the workshop. A 3-hourly workshop was provided for the recruited subjects. The research assistant conducted the questionnaire within one week before the training workshop and within one week after the training workshop.

Data Collection and Instruments

The AMT was conducted during the recruitment period for assessment of the subjects' mental state. The questionnaire consisted of three parts. The first part of the questionnaire consisted of the demographic information; the second part was the Chinese version of the Alzheimer's Disease Knowledge Scale (ADKS) whereas the third part was the modified Dementia Worry Scale (MDWS). The Chinese version of the ADKS was used to assess the knowledge of the disease. The MDWS was used to assess the subjects' worries about dementia. Permissions were granted from the authors to use the above assessment tools.

Data analysis

IBM SPSS statistics for Windows, version 26 was used to analyze the data. Descriptive statistics, including the number and percentages were used to describe the socio-demographic characteristics of the participants. Mann-Whitney U Test and Kruskal-Wallis Test were used to test the relationship between demographic characteristics and knowledge of dementia in pre-test and post-test, as well as the relationship of the worry of dementia.

Statistical test was conducted to test the significance of the change of knowledge score. Shapiro-Wilk test was used to test for normality. Hypothesis of normality was rejected if p-

value was less than 0.05. Non-parametric Wilcoxon Signed Rank Test was used to test for significance.

It was hypothesized that the increase in knowledge of the disease minimized the worry of dementia. Simple linear regression was used to test for such hypothesis, with worry score in post-test as dependent variable and knowledge score in post-test as independent variable. The R2 value indicated how much of the total variation in the dependent variable, worry level, could be explained by the independent variable, knowledge score.

Ethical considerations

Ethics approval was obtained from the recruited elderly centres and the Ethics Committee of Caritas Institute of Higher Education prior to the study. Before the participants signed the consent form, all of them were fully informed of the purposes of the study, including the principles of recruitment and procedure of the study. The participants were informed that participation was strictly voluntary, and they might withdraw any time without any loss of benefits. The written consent form contained detailed information on the purpose and nature of the study, the right of confidentiality, and the right to withdraw.

Results

Participants' Characteristics

There were 197 older people showed interests in the training workshop, however, only 192 participants were included in the initial screening, as the AMT of five of them were under 6. Of the 192 participants, 177 attended the training workshop. However, 28 of them were further excluded because twenty-five questionnaires were found to have unmatched data and three of them were found to have age under 65 in the final check. Among the 149 successful data, majority of respondents were female (80.5%) and 19.5% were male. Most of them fell on age 65-70 (38.3%). Almost half of the subjects were married (47.1%) and completed secondary school (54.4%). One-fifth of them finished university studies (20.1%). Although 27 participants (18.1%) stated they got family members suffering from dementia, only 6 participants (4%) were taking care of demented family members at time of research. Six of the participants (4%) stated they had experience in caring demented family members.

Knowledge Score in Alzheimer's Disease Knowledge Scale (ADKS)

Before the training, the overall mean score of dementia knowledge was 19.42, (SD=2.67). The overall mean score was higher after the training and was 22.28, (SD=2.92). Twenty-four participants decreased in the knowledge score (16.11%), four remained unchanged (4.03%), whereas 119 participants showed an increase in knowledge after the training and corresponded to 79.87% of the total no. of participants (Table 1).

Table 1 Change of knowledge score after attending workshop

Change of knowledge score	No. of person	Percent	Difference (Post-test total score- Pre-test total score)	Frequency
Decrease	24	16.11%	-7	2
			-6	1
			-4	1
			-3	3
			-2	4
			-1	13
No Change	6	4.03%	0	6
Increase	119	79.87%	1	15
			2	18
			3	19
			4	21
			5	20
			6	10
			7	4
			8	9
			9	2
			11	1

Worry of Dementia in Modified Dementia Worries Scale (MDWS)

Before the training, the mean score was 19.7, (SD=8.71), whereas after the training, 81 (54.36%) participants showed a decrease in the level of worry. No change of worry in forty participants (26.85%) and 28 participants (18.79%) showed an increase in worrying about dementia after the training. Overall, there was a decrease in the score after the training and rated 17.52, (SD=7.11) (Table 2).

Table 2 Change of worry score after attending workshop

Change of worry score	No. of person	Percent	Change of score (Post-test - pre-test)	Frequency
Decrease	81	54.36%	-29	1
			-21	1
			-20	1
			-16	2
			-14	1
			-13	2
			-11	1
			-10	1
			-9	4
			-8	6
			-7	1
			-6	5
			-5	6
			-4	7
			-3	10
			-2	20
			-1	12
No change	40	26.85%	0	40
Increase	28	18.79%	1	7
			2	8
			3	5
			4	2
			5	1
			6	1
			8	1
			10	1
			11	1
			12	1

Relationship between knowledge and dementia worrying

To compare the relationship between the knowledge and the dementia worry, it was hypothesised that the increase in knowledge of the disease minimize the worry of dementia. Simple linear regression was used to test for such hypothesis, with worry score in post-test as dependent variable and knowledge score in post-test as independent variable. Hence only 0.4% of worry level could be explained by knowledge of dementia.

Relationship between demographic characteristics and knowledge of dementia

The performance of different age group in pre-test were similar. Nonetheless, after attending the workshop, the younger the participant was, the higher the knowledge score would be.

As for level of education, same trend could be identified in both pre-test and post-test. Moreover, the degree of improvement was more significant in those with higher level of education.

For marital status, it was noted before the training, the mean score of the knowledge of those separated/divorced was lower than those with other marital status. After the training, the null hypothesis was rejected and the knowledge of those separated/divorced group was improved.

It was observed that the worry level of those with family members with dementia and with history of caring for demented family members was significantly higher than those did not.

After the workshop, the worry level of participants with family member with dementia and history of caring demented family member was the same with those do not have family member with dementia and history of caring demented family member.

Discussion

The population is aging, and the number of dementia clients is increasing. Different trainings and workshops are conducted to caregivers, healthcare professionals on the knowledge and skills in caring for the demented clients. However, for those cognitive-intact older people, they are the group of people who may be neglected. The results showed that providing training with correct information to the cognitively intact older people significantly strengthen their concepts about dementia and a reduction in dementia worry.

The relationship between demographic characteristics and dementia knowledge

From the findings of this study, it revealed that demographic characteristics had great relationship to the knowledge of dementia and the effects of training also differed. There is statistically significant change of knowledge score after attending the workshop. Such findings contradicted to previous literature that training of Alzheimer's disease knowledge was not significantly correlated with any of the sociodemographic characteristics (Scerri & Scerri, 2017).

In many studies, age is one of the influencing factors that affected the understandings of dementia. In our study, the knowledge of different age groups in pre-test were similar, nonetheless, after attending the workshop, the younger the participant was, the higher the knowledge score. This finding was supported by few studies (Liu et al. 2019; Scerri & Scerri, 2017). In contrast, Carpenter et al. (2011), found that the knowledge scores tend to be higher with increasing age. In Hong Kong, the young-old group was still socially active and engaged in many community activities, they may not be interested to explore the knowledge of dementia, they may just hearsay or accept what is provided by social media. After the training workshop, correct information was provided, this might increase their awareness towards this disease and the score was higher.

Our study revealed an interesting finding. There was significant difference in the mean knowledge score of the ADKS among the marital status groups ($p=0.04$). The mean knowledge score of dementia for those separated/divorced groups were the lowest compare with those married or singled in the pre-training. Whether or not the trauma after divorce would linger and affect learning new things was in doubt and may be interesting to have further studies.

As for level of education, the mean knowledge score in ADKS for those subjects with university level had higher score (mean score 20.23) before the training when compared with those of informal school (mean score 17.44). The same trend was identified in the post-test.

The degree of improvement was more significant in those higher educational groups. This finding was consistent with previous studies (Liu et al., 2019; Scerri & Scerri, 2017). During the training session, those with higher educational level tend to be more attentive and were also more active in answering questions, they liked to ask questions when they were in doubt. Although improvement was shown in the informal school group immediately after the training, strategies should be made for this group to increase their interests and knowledge on dementia. Less educated older people might not have sufficient knowledge or resources to identify the early signs of dementia, they might think that dementia was just a matter of forgetfulness and tend to neglect the symptoms, and this phenomenon was not uncommon (Liu et al., 2019; Lynn et al., 2017). This group of older people posed great challenges in prevention of and treatment of dementia. Government and stakeholders should enhance the education, with medical and social support for this group of older people.

The effects of training on knowledge of dementia using Alzheimer's Disease Knowledge Scale (ADKS)

The ADKS contains 30 true/false items to assess knowledge about Alzheimer's Disease. One mark is given for each correct answer. The total score is 30.

Dementia often gives people the image that they would steal other people's things, had trouble in handling money, and increased risk of fall. These were reflected in question 14, 22 and 23. The overall score before and after the training were 90 or even higher. When Alzheimer's disease is not yet severe, over 95% of the participant agreed that psychotherapy may help to relieve their depression and anxiety. The high score reflected that generally, most people got a general picture of what dementia people would present with.

There were few questions that most of the participants answered wrongly, the score was low even after training. For question 2 and 16, the percentage of the participants that answered correctly were only 12.08% and 12.75% respectively. After the training, there were slight improvement with 36.24% and 13.42% respectively which were still below the average score. For question 2, they were asked "It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease". Since the cause of Alzheimer's disease is unknown, therefore, there is no certain way that this disease can be prevented. In the community, people are often encouraged to do more physical and mental exercises, to keep the brain active. This may only "reduce" the risk of getting demented, but all these strategies cannot prevent the occurrence of the disease. This is one of the common misconceptions that older people deeply rooted in their mind. In fact, numerous factors associated with overall good health may reduce the risk of dementia but cannot prevent its occurrence. (Alzheimer Society of Canada, 2022; WedMD, 2020). Accurate information regarding dementia should be given to the public. For question 16, most of the participants agreed that "once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care". In fact, people with dementia should not be assumed to have impaired capacity to make their own decision. It is important to educate the public that people with dementia should have their rights to decide what they like, and their autonomy should be respected (Hegde, S., & Ellajosyula, 2016). This misconception would create unnecessary fear towards this disease.

When asking about whether high cholesterol and high blood pressure may increase a person's risk of developing Alzheimer's disease in question 18 and 26, only 54.36% and 48.99% respectively of the participants answered correctly and agreed both are risk factors of having

dementia. After the training, the score of these two questions raised immediately to 83.22% and 81.88% respectively. The participants did not associate dementia with high blood pressure and high cholesterol and yet these are so common in older population. There is growing acceptance of a relationship between cardiovascular disease and Alzheimer disease and it was believed that brain function and blood pressure are deeply connected (Decarli, 2021; Power, et al., 2011). Older people are quite alert about their blood pressure and cholesterol, and some of the participants in the study might suffered from hypertension and/or hypercholesterolemia, when they were told in the training session that these two were the risk factors of getting dementia, they would increase their awareness as these factors are so closely related to their daily life and they tried to remember. This may explain why the difference of score was so great before and after the training. This also reflected the knowledge deficits. Proper health promotion as well as lifestyle modification should be reinforced. Another question that the score raised greatly after the training was question no. 6, 35.57% of the participants agreed that when people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away. This may be explained by the traditional Chinese culture, the importance of filial piety and intergenerational solidarity. When the older people or the family members have difficulties in caring for themselves, the family members would assist them as much as possible. This was not correct to certain extent for people with dementia, they should be encouraged to do the tasks by themselves as much as they can, to train their brain function and respect them as an adult. This concept should be reinforced in future training.

The effects of training on dementia worries using Modified Dementia Worry Scale (MDWS)

The Modified Dementia Worry Scale is a 12-item measure of dementia-related anxiety. Participants rate how typical each statement is of them using a 5-point scale; The lowest score is 12 and the higher score is 60, higher scores indicate greater dementia-related anxiety. Among the 144 participants, 28 of them yielded 12 (18.8%) before the training and 38 (25.5%) after training. Only one participant scores 60 in the pre-test and 0 in the post-test. The result showed that these group of participants were not too worried about this disease. This result might not truly reflect the situation of the older population in Hong Kong, because for those participated in this study, they were members in the community centres, they were comparatively more active and had their social lives, they might have less worries or they might seek help from their peers. In such case, training might not lessen their worries of getting dementia and only 0.4% of worry level can be explained by knowledge of dementia. However, there were 27 participants had family member with dementia and six of them were currently taking care of their demented family members. Six of them had history of caring demented family members, it is observed that the worry level of those with family members with dementia and with history of caring for demented family members was significantly higher than those do not. With the proper knowledge given in the training workshop, it is noted that after the workshop, the worry level of participants with family member with dementia and history of caring demented family member became the same with those do not have family member with dementia and history of caring demented family member. This indicated if people had better understand of dementia, it might lessen their worries.

Limitations

The findings of the study supported the hypothesis that training may increase the knowledge of dementia of the community dwelling older people and may lessen their dementia worries;

however, one limitation of this study is the small sample size. With the increasing trend of the proportion of elderly aged 65 and over, the number of participants in the current study was difficult to generalize the findings to the older people in Hong Kong. The participants recruited were mainly from community centres, whereas those older people who need to take care of their demented family members might not be able to attend the training workshop, thus the dementia worries might not be truly reflected in the study.

Another limitation was that the training workshop was only one-off and lasted for three hours. Though the content was comprehensive, it might not fully cover all the important information about dementia. The participants showed interests in the topic, however, the concentration span of older people might not allow them to be very attentive even some games and exercises were built-in in the workshop. Sustainability of what they have learnt is also in doubt. In future, shorter duration with few more sections would be more beneficial to them.

Lastly, the instrument was adopted from western countries. Although it was being translated into Chinese and being validated. Some items might not be associated with their daily living and were not too culturally related, such as asking if demented older people were safe to drive the car. Driving in Hong Kong is not as common as western countries for older people. When asked about dementia worries, some older people found to have difficulties in understanding some of the items, the researcher need time to explain clearly to them. The older people also tend to share lots of their own feelings and experiences but not specifically answering what was being asked. A qualitative way or a mixed method of study might be more informative in the future.

Conclusions

This study highlighted the importance of training to the cognitive intact community dwelling older people about dementia. Apart from teaching the caring technique, correct knowledge is equally important especially to fill the knowledge gap and to alleviate unnecessary worries. The findings were able to identify knowledge deficits and worries in some specific groups of older people in the community. It is important to provide the real facts of dementia and stop the myths. In the long run, emphasis should put on those cognitive intact older people who need to take care of their family members at home and not able to attend onsite seminars or lectures to increase their knowledge. When more people in the community have better understanding to this disease, it will improve the quality of life of older people with or without dementia.

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