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Dementia Care Class Increases Confidence of Informal Caregivers in Community-Based Dementia Care

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A B S T R A C T

Dementia develops rapidly each year in line with the increasing number of the world's elderly population. Dementia causes dependence, reduced quality of life, and even disability. Currently, the focus of treatment is carried out by health workers. There is a need for an informal caregiver capacity-building program in community-based dementia care. This study aimed to identify the effect of community based dementia care class on self-confidence among informal caregiver. This study used a pre-experimental pre and post-test with control group design. Sample choosen with purposive sampling consisted of 24 informal caregivers for each intervention and control group. The research instrument used Self-Confidence Questionnaire about Dementia Care Skills with a reliability value of 0.947. The intervention given 4 sessions in 2 days with 45-60 minutes per session. Data analysis used paired t-test and independent t-test. The results showed that there was an effect of dementia care class on the confidence of informal caregivers in community-based dementia care with a value of p=0.000 (p<0.05). These learning models and media can be integrated into elderly posyandu and elderly health programs in healthcare facilities in community-based dementia management.

Kata kunci:

kelas perawatan demensia
berbasis komunitas
caregiver informal
percaya diri

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A B S T R A K

Demensia berkembang pesat setiap tahunnya seiring dengan bertambahnya jumlah penduduk lanjut usia di dunia.Demensia menyebabkan ketergantungan, penurunan kualitas hidup, bahkan kecacatan. Saat ini, fokus pengo batan dilakukan oleh tenaga kesehatan. Ada kebutuhan untuk program peningkatan kapasitas caregiver informal dalam perawatan demensia berbasis masyarakat. Penelitian ini bertujuan untuk mengidentifikasi pengaruh kelas perawatan demensia terhadap kepercayaan diri pada caregiver informal dalam perawatan demensia berbasis komunitas. Penelitian ini menggunakan pre-experimental pre and post-test with control group design. Sampel dipilih dengan purposive sampling terdiri dari 24 caregiver informal untuk masing-masing kelompok intervensi dan kontrol. Instrumen penelitian menggunakan Self-Confidence Questionnaire tentang Dementia Care Skills dengan nilai reliabilitas 0,947. Intervensi diberikan 4 sesi dalam 2 hari dengan durasi 45-60 menit per sesi. Analisis data menggunakan uji t berpasangan dan uji t independen. Hasil penelitian menunjukkan bahwa ada pengaruh kelas perawatan demensia terhadap kepercayaan diri caregiver informal dalam perawatan demensia berbasis komunitas dengan nilai p=0,000 (p<0,05). Model dan media pembelajaran ini dapat diintegrasikan ke dalam posyandu lansia dan program kesehatan lansia di fasilitas kesehatan dalam penanganan demensia berbasis komunitas.

INTRODUCTION

Dementia is the most common neurodegenerative disease. Dementia in the elderly has a high incidence rate and develops rapidly and severe. Dementia can bring tremendous pressure on global health and social systems and thus requires immediate attention (C. Wang et al., 2022). Globally, more than 50 million people have dementia, and one new case occurs every 3 seconds. The COVID-19 pandemic and the discovery of various cases of communicable and infectious diseases have created major concerns for people living with dementia (H. Wang et al., 2020).

The world population suffering from dementia can grow by up to 10 million per year. The ratio of people with dementia in the elderly population over 65 years is 5% -8%. According to the predictions of the World Health Organization (WHO), the global population suffering from dementia will reach 82 million in 2030, and 152 million in 2050. The incidence of dementia increases significantly with increasing age, therefore, the incidence of dementia increases with increasing age expectancy average life. (C. Wang et al., 2022).

The increase in dementia cases is global, but due to different patterns in exposure to risk factors and access to health services, a greater increase is found in middle-income countries (Peters et al., 2019). The Ministry of Health of the Republic of Indonesia stated that Indonesia is entering a period *of an aging population* where there is an increase in life expectancy that goes hand in hand with an increase in the number of elderly people. The number of elderly people has increased from 18 million people (7.56%) to 25.9 million people (9.7%) in 2019 and is expected to reach 48.2 million people (15.77%) in 2035 (Immanuel & Natalia, 2021). An increase in life expectancy and the elderly population is of course related to the high rate of people with dementia. In Indonesia, in 2016 there were 1.2 million people with dementia and it is estimated that this will continue to increase to 2 million in 2030 and 4 million people in 2050. (Juniarti et al., 2021).

Hypertension, diabetes mellitus, and mental disorders are some of the risk factors that can cause the elderly to experience dementia. Based on the Health Profile of Kudus Regency in 2020, the coverage of health services for the elderly who received health screening related to hypertension, diabetes mellitus, mental disorders, and other non-communicable diseases in 2020 only reached 28,440 elderly (30.4%). The working area of the UPTD of the Dawe Health Center and the working area of the UPTD of the Kaliwungu Health Center are the areas with the highest number of elderly in Kudus with a total of 7,728 elderly (8.26%) and 6,497 elderly (6.94%). In the working area of the UPTD Dawe Health Center, only 4% of the elderly received health screening according to standards. The highest number of cases of hypertension aged more than 15 years was 18,019 cases, the number of cases of diabetes mellitus was 1,398 cases (22.15%) and the number of cases of people with severe mental disorders was 169 cases (19.2%). In the working area of the Kaliwungu Health Center UPTD, only 4.4% of the elderly received health screening according to standards. The highest number of cases of hypertension aged more than 15 years was 17,808 cases (7.8%), the highest number of cases of diabetes mellitus was 1,382 cases (21.9%) and the highest number of cases of people with severe mental disorders was 169 cases (19.2%)) (DKK Kudus, 2021) Based on data on the risk factors for dementia, the researchers determined the research location in the working area of the UPTD Puskesmas Dawe and Kaliwungu, Kudus Regency.

Dementia causes dependence and reduced quality of life in the elderly. Dementia is a syndrome or disease with a set of symptoms consisting of a decrease in global cognitive power that is not accompanied by an impaired level of consciousness. Dementia contributes 11.2% to disability cases in subjects aged 60 years and over; greater than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5%), and all types of cancer (2.4%). Alzheimer's disease is the main cause of dementia (50-75%) in old age (Ainun et al., 2018).

The elderly with dementia usually have symptoms such as impaired daily memory, concentration, planning or organization, language skills, visuospatial abilities, and orientation. With the development of dementia, the elderly will experience difficulties in meeting their basic needs, thus increasing the dependency ratio in carrying out daily activities. Declining cognitive function in the elderly is also influenced by lifestyle factors and brain stimulation, including lack of cognitive and physical activity, impaired social relationships, and unhealthy eating patterns (Juniarti et al., 2021).

Research shows that up to 90% of people with dementia in long-term care have hearing loss and >50% have a visual impairment. Hearing/vision impairment among people with dementia is associated with reduced quality of life and increased agitation, hallucinations, aggression and depression, social isolation, cognitive decline, and a higher need for care (Dawes et al., 2021). Dementia patient care requires high costs. The results of previous research globally showed that the cost of dementia care in 2010 was around $604bn or could reach nine million rupiahs per month. Not only financial problems, but the emotional and physical demands experienced by people with dementia can also become stressors for caring families, causing adverse psychological and physical outcomes (Saini & Maiti, 2018).

There are nine risk factors modeled by the Lancet Commission that have the potential to be modified related to dementia prevention, intervention, and care, namely, lack of education, hypertension, hearing loss, smoking, obesity, depression, lack of physical activity, diabetes, and low social contact (Livingston et al., 2020). Currently, the treatment of dementia only focuses on health workers without optimizing community empowerment through health cadres as *caregiver*s for the elderly with dementia. To overcome dementia, the community must increase understanding and awareness of dementia disorders, raise awareness of the dangers of dementia, and carry out appropriate management of people with dementia (Muliatie et al., 2021).

Dementia Care Class (DCC) is a comprehensive training program for health cadres as *caregivers informal* to have competence in caring for elderly people with dementia. Through the DCC program, the elderly are taught to recognize dementia and its early symptoms, conduct dementia screening, carry out efforts to prevent and treat dementia, perform brain exercises as prevention of dementia, and accompany the elderly with dementia. The results of previous research indicate that training for health cadres is very useful and can improve the ability of cadres to perform long-term care for the elderly (Nugraha et al., 2019).

Nurses as providers of nursing care and educators have a role and responsibility to be able to overcome dementia problems by providing training to health cadres to increase the knowledge, skills, attitudes, perceptions, and *self-confidence of health cadres in providing care (Hasan et al., 2020).* Currently, no research evaluates the effectiveness of

health cadre training on cadre confidence in caring for dementia patients. The purpose of this research is to identify the influence *of dementia care classes* on knowledge, attitudes, and confidence in community-based dementia care for informal caregivers in the Kudus District

METHODS

Participant characteristics and research design

The research design uses pre-experiments pre and post-test with a control group. The Independent variable is dementia care class, and the dependent variable is self onfidence in dementia care. This research was conducted from October 2022 - April 2023 in the working area of the Dawe Health Center UPTD for the intervention group and the Kaliwungu Health Center UPTD for the control group. The inclusion criteria in this study were active health cadres in their respective areas, aged 19-59 years (adult age category), minimum education level of elementary school, and able to read, write and communicate in Indonesian.

Sampling procedures

The number of samples was 24 respondents for each of the intervention and control groups. Sampling technique used by this study was purposive sampling. This research has passed a research ethics review from the Health Research Ethics Commission at the Muhammadiyah University of Kudus number 38/Z-5/KEPK/UMKU/XII/2022 on 12 December 2022.

Sample size, power, and precision

The sample size in this study was determined based on the sample calculation formula to test the hypothesis of two paired populations and obtained n1 and n2 values of 23.71 and rounded up to 24.

The research instrument uses Self-Confidence about Dementia Care Skills Questionnaire with 15 items statements with answer choices I can't do it at all, I can't do it well, I'm sure, I might be able to do it, and I can do it very well (Likert scale) to identify confidence in dementia care skills. The lowest self-confidence score is 15 and the highest self-confidence score is 75 with a reliability value of 0.947 (M. Wang et al., 2020). Researchers do back translation (translating into Indonesian and then re-translating into English by linguists) and content validity by experts or experts on the questionnaire before use.

Measures and covariates

Researchers provide research information to prospective respondents before research. Researchers asked prospective respondents to fill out a consent form if they were willing to be research respondents. Researchers provide interventions in the form of dementia care classes to the intervention group as many as 4 sessions in 2 days with a duration of 45-60 minutes per session. Researchers compiled a community-based dementia care guidebook as a media to support interventions. The stages of the intervention are as follows:

1. Session 1: getting to know dementia (lectures, discussions, and questions and answers)
2. Pre-session 2: early symptoms of dementia (interactive video)
3. Session 2: dementia screening (demonstrations, case studies)
4. Session 3: prevention and care of dementia in the community through the elderly Posyandu (discussion lectures, and questions and answers)
5. Pre-session 4: brain exercise as prevention of dementia (interactive video)
6. Session 4: tips on caring for and assisting people with dementia (lectures, discussions, and questions and answers)

Post session 4: caregiver experiences caring for people with dementia (interactive video).

Data analysis

The researcher conducted a different test of mean self-confidence before and after the intervention in both the intervention and control groups using a paired t-test because the data were normally distributed (p>005). Analysis of the effect of the intervention on self-confidence was seen from the results of the independent t-test because the data were normally distributed (p>0.05). The p-value is determined based on equal variance assumed because the variance of the data is homogeneous (p>0.05).

RESULTS AND DISCUSSION

Table 1 explains that the average age of informal caregivers in the intervention group was 38.42 years with an SD of 8.667 and the length of time being a health worker was 5.79 years with an SD of 7.229. The average age of informal caregivers in the control group was 45.17 years with an SD of 10.961 and the length of time they had been health cadres was 5.46 years with an SD of 4.539.

Table 1.
Characteristics of informal caregivers based on age and length of time as a health worker (n=48)

Characteristics	Intervention		Control	
	Mean	SD	Mean	SD
Age	38,42	8,667	45,17	10,961
Been a health cadre for a long time	5,79	7,229	5,46	4,539

Table 2 describes that all health cadres in the intervention group were female, namely 24 people (100%), the majority were married, namely 21 people (87.5%), and high school/equivalent educational background, namely 13 people (54.2 %), worked as housewives, namely 13 people (54.2%), did not have income, namely 16 people (66.7%), did not have experience in dementia care training, namely 15 people (62.5%), did not have experience caring for people with dementia as many as 14 people (58.3%). the majority of health cadres in the control group were female, namely, 23 people (95.8%), married, namely 22 people (91.7%), had high school/equivalent educational background, namely 11 people (45.8%), working as housewives, namely 12 people (50%), having no income, namely, 12 people (50%), having no experience of dementia care training, namely 15 people (62.5%), having no experience caring for people with dementia as many as 13 people (54.2%).

Table 2.
Characteristics of informal caregivers based on gender, marital status, education, employment, income, and training experience (n=48)

Characteristics	Intervention		Control	
	f	%	f	%
Gender				
Man	0	0	1	4,2
Woman	24	100	23	95,8
Marital status				
Not/not married	2	0	1	4,2
Marry	21	97	22	91,7
widow/doubt	1	3	1	4,2
Level of education				
SD/equivalent	0	0	1	4,2
Middle school/equivalent	5	20,8	9	37,5
SMA/equivalent	13	54,2	11	45,8
College	6	25	3	12,5
Work				
Doesn't work	5	20,8	1	4,2
Housewife	13	54,2	12	50
Private officer	0	0	1	4,2
Self-employed	3	12,5	3	12,5
Trader	1	4,2	0	0
Laborer	0	0	2	8,3
Teacher/lecturer	1	4,2	2	8,3
Others	1	4,2	3	12,5
Income				
No income	16	66,7	12	50
< Rp. 2,290,995,-*	5	20,8	9	37,5
≥ Rp. 2,290,995,-*	3	12,5	3	12,5
Training experience				
Once	9	37,5	9	37,5
Never	15	62,5	15	62,5
Experience treating ODD				
Once	10	41,7	11	45,8
Never	14	58,3	13	54,2
Total	**24**	**100**	**24**	**100**

Table 3 explains that the average confidence in dementia care was 47.46 with an SD of 12.518 before the intervention and 55.92 with an SD of 7.419 after the intervention. The average confidence in dementia care was 37.92 with an SD of 14.990 before intervention and 36.21 with an SD of 15.166.

Table 4 illustrates that there was a significant difference in confidence in dementia care before and after the intervention in the intervention group with a value of p = 0.005 (p <0.05). However, it did not show a significant difference in confidence in dementia care before and after the intervention in the control group with p = 0.531 (p> 0.05).

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The mean age of health cadres based on table 1 in the intervention group was mean ± SD 38.42 ± 8.667 and in the control group mean ± SD 45.17 ± 10.961. The selection of health cadres of productive age is very important. Previous research mentions *caregiver* with Older dementia has a higher burden of care when patients experience greater impairment of functional autonomy and the presence of symptoms of apathy and irritability. There needs to be an effort to identify *caregiver*s for at-risk elderly. More attention and support should be given to *caregivers informal* who may experience fatigue (Tsai et al., 2021).

The majority of the sex of health cadres in table 2 shows that in the intervention group, 24 cadres (100%) were female, while in the control group, 23 cadres (95.8%) were female, and only 1 cadre (4.2%) who are male. Much is known about the demands of care for people with dementia and their impact on *caregiver*s, but the aspects of sex and gender received less attention. Previous studies have shown that there are sex and gender differences in parenting burden (Xiong et al., 2020). Other research validates much of the previous evidence that women are better than men at serving as *caregiver*s informal services for parents with caregiving needs (Cohen et al., 2019).

Table 3.
Description of the confidence of informal caregivers in community-based dementia care in the intervention and control groups before and after the intervention (n=48)

Variable	Intervention			Control		
	Mean	SD	95% CI	Mean	SD	95% CI
Self-confidence						
Before	47,46	12,518	42,17-52,74	37,92	14,99	31,59-44,25
After	55,92	7,419	52,78-59,05	36,21	15,166	29,80-42,61

Table 4.
Differences informal caregiver confidence in community-based dementia care before and after intervention in the intervention and control groups

Variable	Mean	SD	MD	p-value
Self-confidence				
Intervention			8,36	0,005
Before	47,46	12,518		
After	55,92	7,419		
Control				
Before	37,92	14,99	-1,71	0,531
After	36,21	15,166		

Table 5.
Influence*dementia care class* on the confidence of informal caregivers in community-based dementia care

Variable	Mean	SD	p-value
Skills			
Intervention	55,92	7,419	0,000
Control	36,21	15,166	
Difference	19,71		

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The marital status of health cadres in table 2 shows that in the intervention and control groups, the majority had married status whereas the intervention group consisted of 21 cadres (97%) while in the control group, there were 22 cadres (91.7%). Marital status is one of the factors that influence the perception of the burden experienced *by the caregiver* (Strunoiu et al., 2019) Research shows that marital status and social support are owned by *caregiver* be significant predictors of the well-being *of caregivers* who care for the elderly (Recep & Kartal, 2019)

The level of education is an important factor in the ability *of caregiver*s to informal care for dementia patients. In table 2 it is found that the majority of health cadres have high school/equivalent education levels where in the intervention group there were 13 cadres (54.2%) while in the control group, there were 11 cadres (45.8%). Previous studies have shown that a higher level of education affects the lower burden of care experienced by *caregivers* (Strunoiu et al., 2019). Education can reduce the burden of care and improve the quality of life *for caregivers* (Hekmatpou et al., 2019)

The majority of jobs held by health cadres in table 2 shows that most of the cadres work as housewives. In the intervention group, 13 cadres (54.2%) were housewives, while in the control group, 12 cadres (50%) also worked as housewives. *Caregiver* informal is a rewarding but demanding role. Some of the difficulties that may be experienced as *caregiver* informality is depersonalization and difficulty in fulfilling personal achievements (Gérain & Zech, 2019)

The average income is based on table 2 in the intervention group, as many as 16 respondents (66.7%) had no income, while in the control group, there were 12 respondents (50%) had no income. Health cader is considered as a reference in handling various health problems including dementia. Theoretically, there is a positive relationship between socioeconomic status and individual achievement and activity, but the results of previous research by Aderita et al., (2019) stated that there is no relationship between the socioeconomic status of health cadres and the activity of health cadres.

Table 1 shows the average length of time being a health cadre in the intervention group, namely 5.79 years, and in the control group, the average length of being a health cadre is 5.46 years. The length of time being a cadre has a relationship with the cadre's experience in improving health efforts. Health cadres play an important role by bridging the gap between health service providers and the community in providing health-related information (Mediani et al., 2022).

Table 2 shows that 15 health cadres (62.5%) in the intervention group had never attended the training. The same thing was found in the control group where as many as 15 health cadres (62.5%) also had no experience in participating in training. One of the efforts to create a healthy Indonesian society is to empower the community or cadres who are willing to voluntarily get involved in posyandu issues. Research states that cadre training is effective in increasing the knowledge, attitudes, and skills of health cadres (Tampake et al., 2021).

The experience of caring for people with dementia can have a close relationship with the knowledge, attitudes, and confidence of health workers caring for people with dementia. Results from table 5.2 in the intervention group as many as 14 health cadres (58.3%) had no experience caring for people with dementia. In the control group, 13 health cadres (54.2%) had no experience caring for people with dementia. The occupation and behavior of cadres are determining factors that influence their role of cadres. The results of the study suggest steps to increase the knowledge of cadres through assistance programs and health education for cadres, especially those related to the skills needed (Ratnasari et al., 2019).

Confidence affects the readiness *of caregivers* in treating patients (Vellone et al., 2020). The level of self-confidence of health cadres in table 3 shows that before giving the intervention the health cadres in the intervention group had a mean ± SD mean confidence of 47.6 ± 12.518, while in the control group, the health cadre confidence had a mean mean ± SD of 37.92 ± 14. 99. After giving the intervention to the health cadres, it was found that the intervention group had a mean ± SD mean confidence of 55.92 ± 7.419, while in the control group, the health cadre confidence had a mean ± SD mean of 36.21 ± 15.166. Confidence is an important component in supporting the success of cadres in efforts to treat dementia. Confidence generally appears when a person is going to do or be involved in a certain activity where his mind is directed to achieve the results he wants. Previous research has shown that self-confidence has an important role in a person's ability to develop his abilities and achievements (Septiani & Purwanto, 2020).

The self-confiden*t caregiver* has an important role in fulfilling the self-care needs of patients (Vellone et al., 2020). Table 4 shows that there were significant differences in confidence in dementia care before and after the intervention in the intervention group with a value of p = 0.005 (p <0.05). However, in the control group, there was no significant difference in self-confidence before and after the intervention with a value of p=0.531 (p>0.05). The results of this study are supported by previous research which states that training programs can lead to increased active coping, knowledge, and caregiver self-confidence (Van Den Heuvel et al., 2002)

The results of previous studies mentioned that the self-confidence *of the caregiver* is shaped by the type of illness the patient is being treated for and the caregiver's values and relationship with the patient. Confidence-*caregiver* is also influenced by needs, sources, and strength of support received (Soroka et al., 2018). *Caregivers informal* should be trained and enrolled in intervention programs by nurses and doctors. Through training programs provided by professionals and familiar with life circumstances and problems *Caregivers informal* and patients can improve their abilities *to care for a caregiver* the patient (Van Den Heuvel et al., 2002).

Caregiver self-confidence gets more attention compared to other dimensions of terminal illness care (Soroka et al., 2018).Table 5.5. shows that there is an influence *of dementia care class* significantly on the self-confidence *of caregivers informal* in community-based dementia care with a value of p=0.000 (p<0.05). The results of this study are supported by previous research which states that *caregivers* can experience a progressive increase in self-confidence through training programs (Prickett et al., 2019). Research by Bangerter et al., (2019) is in line with this research which states that informal caregivers with less education and

without regular health service providers have low self-confidence in seeking health information.

Dementia is not only difficult for patients as sufferers but also becomes an extraordinary burden for caregivers and their families (Dai et al., 2019). *Caregiver informal* plays an important role in supporting the health, well-being, and quality of life of patients with chronic health conditions. Training in treating dementia can increase empathy, knowledge of the experience of living with dementia, and the importance of considering and meeting individual needs. Effective training is tailored to the needs of participants, delivered face-to-face by experienced facilitators, is interactive, and embedded in a supportive organizational culture/ethos (Surr et al., 2019).

LIMITATION OF THE STUDY

This study has been successful in investigating the impact of community based dementia care class on self-confidence among informal caregivers. However, some limitations are warranted. This study didn't employ randomization in recruiting and assigning the participants and involved a small sample size. Despite the limitations of this study, this study can provide new insight to use community based dementia care with informal caregiver to help dementia patients.

CONCLUSIONS AND SUGGESTIONS

There is an influence *of dementia care class* significantly confidence in community-based dementia care with a value of p = 0.000 (p <0.05). *Dementia Care Class* become one of the innovative programs to increase the capacity of informal caregivers in conducting community-based dementia care. This program can be integrated into the elderly health service program and non-communicable diseases in health care facilities through a community empowerment process. Increasing the knowledge, attitudes, and skills of informal caregivers in providing dementia care in the community is expected to increase public understanding and awareness about dementia, increase the number of new cases of dementia found through early detection of dementia, reduce the number of dementia cases in the community through preventive and promotive efforts, increase the quality of care services in people with dementia. Community-based dementia management can increase community participation in efforts to treat dementia in the community and reduce the negative impacts that arise due to dementia. This intervention can be a reference for health higher education institutions, especially nursing, in developing competence and skills for students in managing dementia. Future research can identify the effect *of dementia care class* on other variables such as perception, readiness, self-efficacy, skills, and behavior in community-based dementia care. Other studies have also analyzed other community-based interventions that can increase knowledge, attitudes, and confidence in community-based dementia care for informal caregivers.

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ETHICAL CONSIDERATIONS

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Conflict of Interest Statement

The authors hereby declacre that there's no conflict of interest in this study, either to any institutions or individuals

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