

Knowledge and Attitudes Towards People with Dementia among General Population in Yogyakarta

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Abstract—*Dementia has become the leading cause of disability in elderly and contributed to the care burden in many countries, including Indonesia. The family and community play the key role in caring and supporting dementia patients. Their knowledge about dementia and attitudes toward dementia patients will impact the quality of care, but studies on this issue are scarce in Indonesia. This study aimed to investigate the knowledge and attitudes toward people with dementia among general population in Yogyakarta. This study was a cross sectional study by using questionnaire survey. Two hundred and ten people from across Yogyakarta attended a free seminar about dementia held in Alzheimer Indonesia in Yogyakarta, Indonesia and filled the questionnaires. The data were collected using the Alzheimer's Disease Knowledge Scale (ADKS), Bryan's Dementia Attitudes Scale (BDAS), and also demographic questionnaire. The result of the study showed that the overall Alzheimer's Disease Knowledge scores of the participants were low compared with scores in a similar study ($M = 17.17$ out of 30 $SD \pm 2,9$, $n = 210$). Statistically, age was the only variable that showed a significant correlation with attitude, while knowledge about dementia did not. It is suggested to include dementia education in general to increase their knowledge about dementia*

Keywords— *attitude, dementia, knowledge, general population*

I. BACKGROUND

Previously, dementia is being ignored by major population, especially in the developing country. However, dementia became the leading cause of disability in elderly worldwide. The number of people with dementia is projected to be three and a quarter million in 2030 [1]. According to World Alzheimer report in 2015, the number of people with dementia is estimated to be 556,000 and this number will noticeably increase in 2030 [1].

In Indonesia, Yogyakarta province is always mentioned as the province that has a high prevalence of dementia, about 20.1% of population with age ≥ 60 years old [1], [2]. Besides, dementia can impact on the health

care system as well as the economic sector of the country. The cost of dementia care will increase or even double as its severity progresses [3].

Indonesia is classified as low-middle income country by the World Bank in the present data. It may describe that there is gap between rural and urban areas in almost all aspects of life. The availability of service of care and information for people with dementia is in a better situation and stigmatization and greatly improved in urban area compared to in rural area [4]. The prevalence of dementia in the rural area of Yogyakarta is higher than it is in the urban area (23.0%: 17.8%) [1], [2]. The data are quite similar to the report from the World Health Organization 2017 [5], that the most people with dementia live in low income and middle income countries, where the case will rise in the future.

In 2016, Ministry of Health of Republic Indonesia launched National Dementia Plan with purpose of improving wellbeing of both caregiver and people with dementia, raising awareness, reducing stigmatization, and reducing risk of dementia [1]. This was the first policy as an initial step in improving the quality of life of the people with dementia in Indonesia. Even though many sectors are involved, the family is the key in providing the care. This may be not only due to cultural characteristic in which filial obligation is their biggest motivation, but people with dementia need special care to face behavioral and psychological symptoms [6]. Thus, it is expected that the family and community play a key role in caring for and supporting them.

Good attitude and knowledge toward people with dementia are needed to improve their quality of life and survival rate. Some studies have reported that many demographic characteristics are highly correlated with knowledge and attitude toward people with dementia. However, those correlated factors in our general population are still unclear, especially as our general population is rather diverse and has a unique culture. People might not have an adequate knowledge and a good attitude to provide care for people with dementia.

It is important to know the family and caregiver's knowledge and attitude so that the information can be used to effectively improve the public health policies and intervention. This study aimed to investigate the knowledge

and attitudes toward people with dementia among general population in Yogyakarta and its correlation to their demographic characteristic.

II. LITERATURE REVIEW

A. Dementia

In short, dementia is known as a progressive cognitive decline syndrome. This disease is characterized by the loss of memory, usually short-term memory, difficulty to complete a complex task, disability in spatial orientation, difficulty to find words, and behavioral disorder. Dementia can be caused by degenerative and non-degenerative disease. The dementia that is caused by non-degenerative disease is reversible, while dementia that is caused by other causes is otherwise [7]. This disease can develop into 3 stages with survival times ranging between 2.90 and 7 years for mild dementia, 1.5 to 3 years for moderate dementia, and 1.4 to 2.4 years for severe dementia [8].

Behavioral and Psychological Symptom Disease (BPSD) can occur due to dementia progression that consists of biological, psychological, and social disturbances [9]. BPSD can be seen as 1) emotional disorder with negative side, such as anger, hopelessness, depression, and low self-esteem; 2) delusions, commonly with self neglect, suspicions, and misidentification; 3) perception disorder such as visual hallucination; 4) impaired motor function either in a form of retardation, such as slow movement and speech, or hypermotor activity such as more frequent movement; 5) change in circadian rhythm like change in sleep pattern; and 6) eating disorder, such as anorexia and hyperphagia. Physically, people with dementia may experience pain, swallowing or eating problem, shortness of breath, pressure sores, agitation, and infections [1]. Caring for people with dementia is also challenged by stigmatization and under developed facility [10,11,12,13].

B. Knowledge toward people with dementia

The huge number of people with dementia demands our society to be knowledgeable about this disease. Some literatures noted that lack of public understanding about dementia can be described by their perception that dementia is a part of normal aging [10,12,14,15]. Our society also needs to acquire knowledge regarding behavioral and psychological symptoms of Alzheimer’s disease, such as BPSD, the aggression, and wandering, so they can improve the care management for people with dementia.

High level of knowledge in dementia topic can lead to a positive attitude and opposite of attitude according to another study [16,17]. Reference [10] suggested that the effective ways to reach public knowledge about dementia are by focused group discussion or group support and by initiating early education about this topic in schools. By doing so, it can reduce negative impact of knowing the disease, in which they would be stressed about it instead of coping it successfully.

The instruments used to measure knowledge toward people with dementia are listed in Table I. Additionally, number of studies have been carried out on correlated factors of knowledge toward people with dementia. The factors were

gender, religion, knowing someone with dementia, level of education, marital status, and age [12,18].

TABLE I. SCALE TO MEASURE KNOWLEDGE TOWARD PEOPLE WITH DEMENTIA

| Source | Title | Number of items | Purpose and content | Limitation |
|---|---|---|--|---|
| Palmore (1977) [19] | Fact on Aging: A short quiz | 25 items (T or S) less than 5 min. to complete | To cover the basic physical, mental, and social facts and the most common misconceptions about aging | Not specific in AD - Not specific for health professionals. |
| Barret et al. (1997) [20] | UAB, AD knowledge test for health professionals | 12 items of MCQ | To measure the knowledge of health professionals about AD | Not covering about caregiving |
| Dieckmann, Zarit, Zarit, & Gatz (1988) [21] | The Alzheimer’s disease knowledge test (ADKT) | 20 items of MCQ with ‘I don’t know’ choice | To assess the level of knowledge of Alzheimer’s disease of caregivers, mental health professionals, nursing home staff, and other individual. | Question about aluminium is not relevant for current practice. There are two irrelevant questions to Indonesian setting (about epidemiology in US and Medicare) |
| Bryans et al. (2003) [22] | Dementia knowledge quiz for nurses | 14 items of MCQ derived from Barret et al. 1997 & Dieckmann et al. 1988 | To test current level of knowledge of the nurses about: epidemiology, diagnosis, and management of dementia | There is one question specific for UK nurses (asking the prevalence of AD in UK). |
| Kuhn, King, & Fulton (2005) [23] | Knowledge about memory loss and care (KAMLC) test | 15 items | A test to assess the knowledge of family caregivers concerning memory loss, the early stage of AD, and related care issue | - Not specific in AD - For family caregivers |
| Carpen, Balsis, Otilingam, Hanson, & Gatz (2009) [24] | The Alzheimer’s disease knowledge scale (ADKS) | 30 items (T or F), 5-10 minutes to complete | Content and psychometric update to ADKT: risk factors, assessment and diagnosis symptoms, course, life impact, care giving, treatment and management | One question about driving which is quite uncommon in Indonesian setting |

C. Attitude toward people with dementia

There are no studies about attitude toward people with dementia found in our community. In some cultures, elderly

is recognized as someone who has to be respected and family has a responsibility to take care of them, including their medical issues. In terms of caring for people with dementia, the family needs to identify the previous relationship of people with dementia which can be useful in determining the current behavior. Furthermore, the related and significant person can help people with dementia [25].

Some studies found that positive attitude will rise according to the high level of knowledge of dementia [16,17]. The other factors that correlate with an attitude toward people with dementia were age, gender, knowledge, and family burden factor [10,14,18,26].

Some instruments to measure attitude toward people with dementia were Bryans' DAS (BDAS), Alzheimer's Disease Questionnaire (ADQ), and Attitudes toward Aggression Scale (ATAS). BDAS is appropriate for us to investigate the general population's attitude in the Indonesian setting. Items 4 and 5 will need to be rewarded and included in the "Optimism" attitudes toward AD patients, and there is no instruction for reversing the score for negative statements of attitudes. This makes it difficult to compare the total score from negative attitudes and positive attitudes from studies using the same scale [22].

Then, Alzheimer's Disease Questionnaire (ADQ,) which consists 19-item attitudes scale developed by [27], measures "hope" and "person-centered care" in dementia. The statements in the ADQ are more appropriate for residential aged care. The Attitudes toward Aggression Scale (ATAS) was developed by [28] and consists of 18 items that specifically measure the attitudes of staff regarding aggressive behavior in dementia patients. Both of ADQ and ATAS were rejected from this study because those measures were not appropriate for the study's objectives.

III. METHOD OF THE STUDY

This was a cross-sectional survey to measure general population's attitude and knowledge toward people with dementia. A survey was conducted in September 2018, with involving 213 people who attended a free seminar about dementia that was held by Alzheimer Indonesia in Yogyakarta, Indonesia. Among those participants, some were excluded because of incomplete data. In the final analysis, a total of 210 ADKS questionnaires and 203 participants for BDAS were included.

The data were collected using the Alzheimer's Disease Knowledge Scale (ADKS), Bryan's Dementia Attitudes Scale (BDAS), and the demographic questionnaire. The demographic characteristic factors that might be correlated with knowledge and attitude toward people with dementia are age, education level, sex, having family suffered from dementia, and experience of previous seminar in dementia. All of those data were nominal, except for the level of education that was a categorical data.

The ADKS by [24] was used to investigate current knowledge of Alzheimer Disease. This instrument consists of 30 true/false questions with contents: risk factors, assessment and diagnosis, symptoms, course, life impact, care giving, treatment and management of people with AD. The total score was calculated by adding scores for each item ranging from 0 to 30. The interpretation of this scale is a higher score

indicates better knowledge [29]. Meanwhile, Bryan's DAS was used to measure attitude towards AD people with 10 Likert items (1-5). This questionnaire was divided into "optimism" (1, 3, 4, 5, 6, and 8) and "pessimism" (2, 7, 9, and 10) items categories. Indonesian versions of ADKS and Bryan's DAS were through of the transcultural adaptation process in the previous study by Mulyani (2009). Both of those have good validity and are acceptable used in Indonesia setting. The correlation coefficient and internal consistency for the ADKS in the previous pilot study was were 0.68 and 0.13 ($r = 0.68$; $\alpha = 0.13$). Meanwhile, internal consistency of Bryans' DAS was calculated from the two attitude factors, namely "Optimism" ($\alpha = 0.62$) and "Pessimism" ($\alpha = 0.52$) with correlation coefficient was of 0.33 ($r = 0.33$).

Before the seminar was started, respondents were asked to fill out the consent and questionnaire anonymously in about 20 minutes. The respondents were voluntarily to decided toon joining the research. Then, descriptive analysis was undertaken for all the data. Pearson correlation was used to analyze the correlation between attitude and knowledge towards people with dementia and the demographic variables.

IV. RESULTS AND ANALYSIS

A. Result

Three hundred packets of questionnaires were distributed to participants who attended the seminar and only 210 ADKS and 203 BDAS questionnaires could be analyzed after input and cleaning process.

TABLE II. DEMOGRAPHIC CHARACTERISTIC OF THE RESPONDENTS ($N=210$)

| Characteristic | Frequency (%) |
|---|---------------|
| Age | |
| 17-24 | 72 (34.28) |
| 25-40 | 10 (4.76) |
| 41-64 | 78 (37.14) |
| >64 | 50 (23.80) |
| Mean age | 45.69 |
| SD | 20.50 |
| Sex | |
| Male | 40 (18.8) |
| Female | 170 (80.8) |
| Family member with dementia | |
| Yes | 52 (24.4) |
| No | 161 (75.6) |
| Having experience of attending seminar focused on dementia | |
| Yes | 21 (9.9) |
| No | 192 (90.1) |

^a Source: Primary data

The average age of respondents was 45.69 years old ($SD \pm 20.50$). The number of females (80.8%) was higher than that of males (18.8%). Almost a quarter of respondents (24.4%) were having family member who suffered from dementia and most of them (90.1) never attended a seminar on dementia topic (see Table 1).

TABLE III. KNOWLEDGE AND ATTITUDE OF THE RESPONDENTS TOWARD PEOPLE WITH DEMENTIA

| Variable | Mean+ SD | Min - Max |
|--------------------|--------------|-----------|
| ADKS score (N=210) | 17,17 ± 2,91 | 7 - 23 |
| BADS Score (N=203) | 22,03 ± 4,16 | 13 - 30 |
| Optimism | 10.58 ± 2,46 | 6 - 42 |
| Pessimism | 11.31 ± 2,55 | 6 - 19 |

Source: Primary data

TABLE IV. CORRELATIONS OF THE VARIABLES TO THE ATTITUDE TOWARD PEOPLE WITH DEMENTIA (N= 210)

| Variable | ADKS score | | BADS score | |
|-----------------------------|------------|---------|------------|---------|
| | t/r score | P value | t/r score | P value |
| ADKS score | - | | -.039 | .583 |
| Age | .065 | .355 | .182* | .010 |
| Sex | 0,610 | .542 | 1,41 | .159 |
| Family member with dementia | -.598 | .550 | -.846 | .399 |
| Experience of seminar | .426 | .671 | -.826 | .410 |

*. Correlation is significant at the 0.01 level (2-tailed).

Source: Primary data

1) Knowledge

Table III presents the distribution of respondents' total scores of ADKS. The total scores were ranging between 7 and 23, out of 30. The overall mean score of dementia knowledge was 17.17 (SD = 2.91) and most respondents (18.6%) were in the score of 17. Half of the ADKS questions were answered correctly by 83.8% respondents. Demographic status, even attitude, did not significantly correlate with the knowledge (Table IV).

2) Attitude

As shown in Table III, total scores of attitudes were ranging from 13 to 30 out of 50. Those scores divided into optimism factor with mean of 10.58 and pessimism factor with mean of 11.31. The result of Pearson correlation testing of attitude (BADS) and demography status, it can be seen that only age that had a significant correlation with attitude toward dementia people ($r = 0.182$, $P = 0.01$). Sex, level of education, having family suffered dementia, and experience of attending seminar on dementia topic did not significantly correlate with attitude (Table IV).

B. Analysis

Half of ADKS questions could be answered correctly by over forty five percent of respondents. In this study, the public's knowledge about dementia ($M = 17.17$, $SD = 2.91$) was lower than in other studies. The similar study by Carpenter et al. (2011) found that older adults ($M = 24.1$), AD caregivers ($M = 22.7$), and students ($M = 20.1$) have better knowledge. Meanwhile, systematic review on 40 articles about public's knowledge of AD and dementia showed that they had poor to very limited level of knowledge in almost half of the articles [14]. There was misconception in the public's understanding about decline of memory in the elderly, which considered to be a normal part of aging and non-preventable [14,15]. In researcher's opinion, this baseline understanding can deteriorate the awareness to get knowledge about dementia. Lack of knowledge and skills related to care provision for people with dementia becomes

one of the ways that increases stress on care providers (family and unprofessional caregiver) and is related to poor quality of life and negative health impact on both care provider and people with dementia [13].

Bryan's DAS (BDAS) scores obtained in this research indicated that general attitudes of population toward AD patients were mostly pessimistic ($M = 11.31$; $SD = 2.55$; $n = 203$). However, it was not clear whether the respondents' attitudes tended to be pessimistic or optimistic, since the mean of optimistic attitudes was 10.58 ($SD = 2.46$) out of 50, which was not much different from pessimistic factor.

The main finding in this study was that age was the only variable that statistically had significant correlation with attitude ($r = 0.183$, $p \text{ value} = .009$). It had positive correlation in which better attitude will arise according to the age. Moreover, statically, people with older ages had a better knowledge than people in the younger group did, even though age still did not show a strong correlation. Ultimately, people with older ages may reflect a realistic attitude toward people with dementia. Previous study of [14] indicated that older adults were more aware of the persistent depressive disorder (dysthymia) that is associated with dementia. Nevertheless, overall result showed that middle aged tend to be more caring.

The result of specific study of the elderly population that examined the correlation between age and attitude toward people with dementia showed that age did not influence their attitudes [30]. Attitude toward people with dementia was also related to ageism in some studies. Young adults who stereotyped people because of age, mostly the elderly, could be explained as a defensive strategy and a denial of death and there is distance in their social lives [26].

Positive correlation between knowledge and attitude was reported by previous study [16,17]. Meanwhile, here we could not prove it. Knowledge had negative correlation, but it was not statistically significant ($r = -0.039$, $p \text{ value} = .583$). This finding was also supported by [10] who did a correlation test on attitude and knowledge among Asian populations. They assumed that getting to know about the disease will have the opposite effect.

Another interesting finding in this research was that experience of attending seminars about dementia, and having family member who suffers from dementia were not significantly correlated with the knowledge and attitude toward people with dementia. Statistically, correlation of those two demographic characteristics was relatively weak. However, this finding is still inconsistent. By contrast, literature review by [14] found that highly educated people were more informed and had better knowledge about this topic. Knowing more about dementia could impact poor attitude. These effects were related to anxiety, fear, even issue avoidance [10].

Women have a better knowledge and attitude toward dementia topic than men do [14,18]. This statement has a similarity to our finding, although it does not reach statistical significance. It could be explained by gender approach analysis, which explains that women most likely take their roles at home because they have a greater family responsibility than men so that it can cause them to spend time on caregiving [31]. Male-spousal caregiver used

problem-focused coping, such as self-mediation and emotional blockage, to provide effective care, so it might be decreasing the stress [32].

Knowing someone with dementia significantly impacted attitude and knowledge [12]. Currently, we have had opposite finding. Even though they had filial bond with people with dementia, their attitudes and knowledge had negative correlation. Mostly, the elderly in our community live together with their families. It means that family caregivers have to spend their times, and even money, to provide special care. It may cause burden and pessimistic attitude toward people with dementia [33]. There were many factors that impact family burden to provide care for people with dementia, such as family support, financial resources, and how they cope with these situations [34]. As we mentioned before, attitude measurement has shown that the total score of pessimistic and optimistic factors had slight difference. One possible reason for optimistic factor could be filial responsibility, as we explained in literature review.

There are some limitations to our study. Incomplete data caused the sample number of each factor to be different. It might affect validity of the result. Fortunately, the number of missing data in our study could be tolerated.

IV. CONCLUSION AND RECOMMENDATION

Overall, general people in Yogyakarta have low knowledge about dementia. Further, their attitudes mostly indicated pessimism. There were positive significant correlations between age and attitude toward people with dementia. Although there was no significant correlation between knowledge and attitude, it is hoped that further evaluation of education about dementia topic in public population can improve their awareness, knowledge, and attitude and reach better management for people with dementia. Nonetheless, that effort should specifically differentiate ages of the population and should be started from the early age for preparing better care in the future in order to eliminate the cultural bias about this disease.

For future research, we suggest adding religion and ethnicity as factors of demography characteristic. In our varied community, it might show different perspective to treat people with dementia and view the disease.

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