



Knowledge about Dementia and its Associated Factors: Study among the Middle-aged Population in Indonesia

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Abstract

BACKGROUND: Dementia is a general term for loss of memory, language, problem solving, and other thinking skills that can interfere with daily life. Dementia is generally experienced by the older people. Nearly 10 million new cases of dementia reported each year, and more than 50% of dementia patients live in low and middle-income countries. With these potentially increasing number of dementia cases, accurate knowledge about dementia is essential for the community as it could be beneficial for the quality of care and reducing its progression.

AIM: This study aimed to assess knowledge about dementia in the middle-aged age group and to determine the sociodemographic factors associated with knowledge about dementia in Indonesia.

METHODS: A cross-sectional survey targeted the middle-aged population (40–59 years old), using an online questionnaire examining sociodemographic characteristics (age, gender, occupation), living arrangements, and the Dementia Knowledge Assessment Scale.

RESULTS: A total of 1147 respondents were examined, revealing that more than 67% of the participants had poor knowledge about dementia. We revealed that female gender, younger age, and higher occupational level were significantly associated with good knowledge about dementia in various subscales. Interestingly, the living arrangements showed no significant association with knowledge about dementia in any subscale.

CONCLUSION: The results emphasize the importance of intensive public health awareness to improve public knowledge about dementia in Indonesia, specifically targeting men and older individuals, as well as those with lower occupational levels.

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Introduction

Dementia has become a global challenge in the last century, along with the rapid growth of the older adult population. This chronic disease is characterized by a progressive and irreversible decline in cognitive functions, mainly affecting older people [1]. There are nearly 10 million new cases of dementia each year, and this number is predicted to increase threefold by 2050 [2]. Approximately 58% of dementia patients live in low and middle-income countries, and this percentage is expected to rise to 68% by 2050 [2]. In Indonesia, 1.2 million people with dementia were reported in 2016, and this number is estimated to increase to 2 million in 2030 and 4 million in 2050 [3].

Dementia is one of the leading causes of disability and dependence among the older adult population worldwide. Lack of awareness

and understanding of dementia can contribute to stigmatization and barriers to diagnosis and care, with physical, psychological, and economic impacts on caregivers, families, and communities [4]. Dementia can be overwhelming, not only for people suffering dementia themselves, but also for their caregivers and families. Inappropriate understanding of dementia can trigger a high cost of treatment, particularly in low- and middle-income countries [2] and is mainly caused by a lack of resources and training for assisting people with dementia.

Several studies have identified insufficient understanding of dementia in the community, not only the general population but also among health-care workers [5], [6], [7], [8]. Many members of the public consider dementia to be a normal part of the aging process [9], [10]. This misconception can hinder the potential prevention, detection, and treatment of dementia. Although there is no definitive cure for dementia,

developing new approaches for preventing or delaying dementia progression are a public health priority [1]. Public knowledge about dementia could be beneficial for the quality of care and reducing its progression.

Accurate knowledge about dementia is essential for society as a whole, particularly among individuals in the middle aged. This age group is preparing to face aging themselves, often while also caring for older adult parents [11] who may be experiencing dementia. Previous studies have reported that many demographic characteristics are highly correlated with knowledge and attitudes toward people with dementia [7], [10]. However, these factors need to be further identified in the general population in Indonesia, mainly because people in Indonesia often still prioritize family-based care for their older adult family members [12]. Thus, determining the understanding of dementia in Indonesian society in a comprehensive manner may have valuable implications.

Although several studies regarding knowledge about dementia have been conducted in Indonesia, these have mainly focused on staff in institutionalized care for older adults, such as caregivers, nurses, medical doctors, and other health-care workers who take care of dementia patients. To the best of our knowledge, research investigating public knowledge about dementia is limited in Indonesia. The current study aimed to assess knowledge about dementia in the middle-aged age group (age range: 40–59 years old) and to determine the sociodemographic factors associated with knowledge about dementia.

Methodology

Sample and population

The current study was designed as a cross-sectional descriptive analysis to assess knowledge about dementia in the general middle-aged population. An online survey was distributed randomly to the Indonesian middle-aged population (40–59 years old) between May and June 2020 (open distribution period of approximately 1 month). The questionnaire was distributed to 2000 email addresses and 1000 WhatsApp contacts and was announced through social media (Facebook and Instagram) for open recruitment of study participants.

Ethical considerations

This study followed the Helsinki Convention's norms and later modifications as well as the uniform requirements for manuscripts submitted to biomedical journals. Researchers ensured that the online data collection process to fully respect and protect personal privacy. Informed consent was provided by

participants before engaging with the questionnaire and all responses were provided with assurance of confidentiality. The survey was set up in a way that the potential participant must click on a “button” or type in a response indicating that he/she has read the consent/assent information and agrees to participate. Once the “button” is selected, the potential participant will be redirected to the research survey questionnaire. That is, the survey questions are not viewed by the participant until he/she clicks on or types in response to indicate his/her voluntary participation.

This study was approved by the Ethical Committee of the Institutional Research Bureau at the Universitas Respati Indonesia, with ethical approval number 009/SK.KEPK/UNR/III/2020.

Variables

Sociodemographic characteristics were assessed as potential moderators of dementia knowledge. The questionnaire included demographic background information such as gender, age, education background, and occupation type. We also identified whether the study participants had older adult family members and whether they lived with them.

The outcome variable in this study is the literacy about dementia measured using the Dementia Knowledge Assessment Scale (DKAS). The DKAS is particularly useful for identifying specific problems with dementia literacy and thereby informing more effective targeting of interventions designed to address knowledge deficits. This study used the final version of 25-item DKAS, which provides a reliable and preliminarily valid scale of dementia knowledge across a range of domains relevant to clinicians, educators, caregivers, and students [13].

The Indonesian language version of DKAS was used to identify the level of knowledge about dementia, consisting of four domains relating to (1) causes and characteristics of dementia, (2) communication and behavior, (3) care consideration, and (4) risk factors and health promotion. The DKAS comprises statements about the syndrome that is factually correct or incorrect, which were developed on the basis of a literature review and an international Delphi study with dementia experts. Respondent's answer using a modified Likert scale with five response options: false, probably false, probably true, true, I don't know. A previous preliminary principal component analysis identified four hypothesized components/subscales within the measure that has been defined [13]. The subscale of causes and characteristics identifies dementia pathology and terminal course. The subscale of communication and behavior, identifying how a person with dementia engages with the world. The subscale of care considerations identifies dementia symptoms relevant to the provision of care. The subscale risk factors and health promotion that defines

the risk factors and conditions that are associated with or mistaken for dementia.

Statistical analysis

Data were analyzed using IBM SPSS Statistics for Windows, version 25.0 (IBM Corp., Chicago, IL, USA). Descriptive statistics were calculated for participants' general characteristics and individual sociodemographic factors. Chi-square analysis was performed to identify bivariate correlations between each identified factor with the dementia knowledge subscale. We divided into two categories as good and poor based on the score of upper quartiles for each subscale of dementia knowledge. Multiple logistic regression analysis was performed to assess the factors' (gender, age, occupation, and living arrangement) association with the dementia knowledge level based on four subscales.

Results

A total of 1157 responses were collected, with a response rate of approximately 39%. Before conducting the data analysis, we excluded all respondents who provided incomplete responses to demographic items. Overall, we excluded 10 (0.08%) of the initial respondents, leaving 1147 cases for analysis.

As shown in Table 1, the average age of the study participants was 48.5 years old with a standard deviation of 5.4 years, and 63.4% of the participants were female. The highest number of occupations was

Table 1: Sociodemographic characteristics of study participants (n = 1147)

Variables	Frequency (%)
Gender	
Male	420 (36.6)
Female	727 (63.4)
Age (years, average: 48.5±5.4)	
40–44	412 (35.9)
45–49	240 (20.9)
50–54	358 (31.2)
55–59	137 (11.9)
Occupation	
Professional	187 (16.3)
Civil employee	290 (25.3)
Private employee	316 (27.6)
Entrepreneur	151 (13.2)
Unemployed	203 (17.7)
Living arrangement	
Living together with older adult	391 (34.1)
Having an older adult family member but not living together	285 (24.8)
No older adult family member at all	471 (41.1)
The subscale of dementia knowledge	
Cause and characteristics (upper quartile score: 6)	
Good	379 (33.0)
Poor	768 (67.0)
Communication and behavior (upper quartile score: 8)	
Good	360 (31.4)
Poor	787 (68.6)
Care considerations (upper quartile score: 5)	
Good	292 (25.5)
Poor	855 (74.5)
Risk factors and health promotion (upper quartile score: 11)	
Good	330 (28.8)
Poor	817 (71.2)

private employees. More than 40% of participants did not have an older adult family member.

Table 2 shows the sociodemographic characteristics and knowledge for each subscale of DKAS. More than 60% of both male and female participants had poor knowledge about dementia in all subscales. Those who were in their 40's had better knowledge about dementia in all subscales than those in 50's. More number of professional workers had good knowledge than other occupational groups in all subscales. Nearly 70% of those living together with older adult had poor knowledge about dementia.

Table 3 shows the associations between dementia knowledge in each subscale and sociodemographic factors. The results indicated that the subscale for causes and characteristics was associated with female gender, with females having twice as much knowledge in this area than males (adjusted odds ratio [aOR] = 2.12, 95% confidence interval [CI] = [1.58, 2.86]). The 40–44-year-old age group (aOR = 1.60, 95% CI = [1.01, 2.55]) and 45–49-year-old age group (aOR = 2.09, 95% CI = [1.27, 3.42]) were associated with better knowledge in this subscale. Regarding occupation, the professional group had 1.5 times better knowledge regarding the causes and characteristics of dementia (aOR = 1.51, 95% CI = [1.03, 2.21]). Conversely, private employees (aOR = 0.69, 95% CI = [0.48, 0.98]), entrepreneurs (aOR = 0.46, 95% CI = [0.29, 0.76]), and unemployed individuals (aOR = 0.38, 95% CI = [0.25, 0.58]) had poorer knowledge about the causes and characteristics of dementia than civil workers.

The sociodemographic factors associated with the communication and behavior subscale were as follows: 45–49-year-old age group (aOR = 1.73, 95% CI = [1.07, 2.78]). In addition, private employees (aOR = 0.61, 95% CI = [0.43, 0.88]), entrepreneurs (aOR = 0.45, 95% CI = [0.28, 0.72]), and unemployed individuals (aOR = 0.53, 95% CI = [0.35, 0.80]) had an inverse association with knowledge about communication and behavior. In the care consideration subscale, we identified a significant association with female gender (aOR = 1.54, 95% CI = [1.12, 2.11]) and professional occupation (aOR = 1.83, 95% CI = [1.22, 2.74]).

The fourth subscale, risk factors and health promotion, was associated with female gender (aOR = 1.36, 95% CI = [1.01, 1.83]) and being unemployed (aOR = 0.54, 95% CI = [0.36, 0.83]). Conversely, professional workers had 1.5 times greater understanding of risk factors and health promotion compared with civil workers (aOR = 1.50, 95% CI = [1.02, 2.22]).

Discussion

The current study sought to determine the knowledge about dementia and identified factors

Table 2: Sociodemographic characteristics and knowledge in each subscale (n = 1147)

Variables	Causes and characteristics		Communication and behavior		Care considerations		Risk factors and health promotion	
	Good, n (%)	Poor, n (%)	Good, n (%)	Poor, n (%)	Good, n (%)	Poor, n (%)	Good, n (%)	Poor, n (%)
Gender								
Male	99 (23.6)	321 (76.4)	106 (25.2)	314 (74.8)	85 (20.2)	335 (79.8)	120 (28.6)	300 (71.4)
Female	280 (38.5)	447 (61.5)	224 (30.8)	503 (69.2)	207 (28.5)	520 (71.5)	240 (33.0)	487 (67.0)
Age (years)								
40–44	142 (34.5)	270 (65.5)	119 (28.9)	293 (71.1)	112 (27.2)	300 (72.8)	135 (32.8)	277 (67.2)
45–49	91 (37.9)	149 (62.1)	76 (31.7)	164 (68.3)	72 (30.0)	168 (70.0)	89 (37.1)	151 (62.9)
50–54	112 (31.3)	246 (68.7)	97 (27.1)	261 (72.9)	79 (22.1)	279 (77.9)	99 (27.7)	259 (72.3)
55–59	34 (24.8)	103 (75.2)	38 (27.7)	99 (72.3)	29 (21.2)	108 (78.8)	37 (27.0)	100 (73.0)
Occupation								
Professional	94 (50.3)	93 (49.7)	78 (41.7)	109 (58.3)	74 (39.6)	113 (60.4)	85 (45.5)	102 (54.5)
Civil employee	115 (39.7)	175 (60.3)	94 (32.4)	196 (67.6)	74 (25.5)	216 (74.5)	106 (36.6)	184 (63.4)
Private employee	92 (29.1)	224 (70.9)	83 (26.3)	233 (73.7)	72 (22.8)	244 (77.2)	87 (27.5)	229 (72.5)
Entrepreneur	29 (19.2)	122 (80.8)	31 (20.5)	120 (79.5)	28 (18.5)	123 (81.5)	31 (20.5)	120 (79.5)
Unemployed	49 (24.1)	154 (75.9)	44 (21.7)	159 (78.3)	44 (21.7)	159 (78.3)	51 (25.1)	152 (74.9)
Living arrangement								
Living together with older adult	120 (30.7)	271 (69.3)	122 (31.2)	269 (68.8)	103 (26.3)	288 (73.7)	95 (26.1)	269 (73.9)
Having an older adult family member but not living together	93 (32.6)	192 (67.4)	101 (35.4)	184 (64.6)	81 (28.4)	204 (71.6)	89 (31.2)	196 (68.8)
No older adult family member at all	166 (35.2)	305 (64.8)	137 (29.1)	334 (70.9)	108 (22.9)	363 (77.1)	146 (31.0)	325 (69.0)

associated with knowledge of dementia in the middle-aged age group using an online survey. We used the convenience of online survey technology to minimize human contact during the COVID-19 pandemic. Data were collected from May to June 2020, achieving a response rate of 39%.

This study revealed that more than 67% of participants had poor knowledge about dementia and we identified a significant association between sociodemographic factors and knowledge about dementia in various subscales. Interestingly, we did not identify a significant association between living arrangement and knowledge about dementia in all subscales. The fact that more than one-third of the study participants lived together with older adult family members was not associated with their knowledge about dementia. The presence of an older adult in the household is a common situation in Indonesia, in which one out of four households is that of an older adult [12].

However, the current findings revealed that this condition was not significantly associated with having a good understanding of dementia, which is a health problem experienced by many older adults. This may be because individuals do not understand what dementia is, and consider dementia, or “Pikun” (in the Indonesian language), to be a normal condition due to the aging process [14]. Therefore, the condition

may not encourage other family members to seek better information about dementia. In accord with this finding, a previous study in the general population in Yogyakarta, Indonesia, also revealed that family bonds were not associated with knowledge and attitudes about dementia [15]. This finding is in contrast with previous studies conducted in other countries, which revealed that intensive contact with older adult family members had a significant effect on knowledge about dementia [7], [8], [16], [17]. This may be due to differences in sociodemographic backgrounds and the situation regarding dementia cases in each country.

Causes and characteristics of dementia

The current results revealed that female gender, younger age (40's), and professional group of occupation were significantly associated with knowledge about the causes and characteristics of dementia. The causes and characteristics of the dementia subscale involve fundamental information relating to the pathology and terminal course of dementia and focuses on the biological and pathological aspects of dementia [6]. Being female, younger age and having a professional occupation were significantly associated with having good knowledge about the causes and characteristics of dementia. In Indonesian culture, women are the major

Table 3: The Association Between Dementia Knowledge Assessment Scale subscales and sociodemographic factors

Variables	Causes and characteristics		Communication and behavior		Care considerations		Risk factors and health promotion	
	OR (95% CI)	aOR (95% CI)	OR (95% CI)	aOR (95% CI)	OR (95% CI)	aOR (95% CI)	OR (95% CI)	aOR (95% CI)
Gender								
Male	Reference		Reference		Reference		Reference	
Female	2.03 (1.55–2.66)	2.12 (1.58–2.86)	1.23 (0.95–1.60)	1.12 (0.84–1.50)	1.57 (1.18–2.09)	1.54 (1.12–2.11)	1.32 (1.01–1.73)	1.36 (1.01–1.83)
Age (years)								
40–44	1.59 (1.03–2.47)	1.60 (1.01–2.55)	1.32 (0.86–2.02)	1.28 (0.82–2.00)	1.39 (0.87–2.21)	1.26 (0.78–2.04)	1.06 (0.69–1.63)	1.01 (0.65–1.59)
45–49	1.85 (1.16–2.95)	2.09 (1.27–3.42)	1.59 (1.01–2.52)	1.73 (1.07–2.78)	1.60 (0.97–2.62)	1.65 (0.99–2.75)	1.21 (0.76–1.92)	1.24 (0.77–2.01)
50–54	1.38 (0.88–2.16)	1.42 (0.89–2.27)	1.03 (0.66–1.61)	1.09 (0.69–1.71)	1.06 (0.65–1.70)	1.09 (0.66–1.78)	0.97 (0.62–1.50)	0.95 (0.60–1.50)
55–59	Reference		Reference		Reference		Reference	
Occupation								
Professional	1.54 (1.06–2.23)	1.51 (1.03–2.21)	1.45 (1.00–2.10)	1.38 (0.94–2.02)	1.91 (1.29–2.84)	1.83 (1.22–2.74)	1.49 (1.02–2.18)	1.50 (1.02–2.22)
Civil employee	Reference		Reference		Reference		Reference	
Private employee	0.63 (0.45–0.88)	0.69 (0.48–0.98)	0.66 (0.47–0.93)	0.61 (0.43–0.88)	0.86 (0.59–1.25)	0.87 (0.59–1.28)	0.74 (0.52–1.06)	0.81 (0.56–1.17)
Entrepreneur	0.36 (0.23–0.58)	0.46 (0.29–0.76)	0.45 (0.28–0.71)	0.45 (0.28–0.72)	0.66 (0.41–1.08)	0.74 (0.45–1.23)	0.54 (0.34–0.86)	0.63 (0.39–1.02)
Unemployed	0.48 (0.33–0.72)	0.38 (0.25–0.58)	0.58 (0.39–0.87)	0.53 (0.35–0.80)	0.81 (0.53–1.24)	0.69 (0.44–1.06)	0.58 (0.38–0.87)	0.54 (0.36–0.83)
Living arrangement								
Living together with older adult	0.81 (0.61–1.08)	0.84 (0.62–1.13)	1.11 (0.83–1.48)	1.20 (0.88–1.63)	1.20 (0.88–1.64)	1.22 (0.88–1.69)	0.71 (0.53–0.97)	0.74 (0.54–1.01)
Having an older adult family member but not living together	0.89 (0.65–1.22)	0.81 (0.58–1.13)	1.34 (0.98–1.83)	1.31 (0.94–1.81)	1.34 (0.95–1.87)	1.27 (0.90–1.79)	1.01 (0.74–1.39)	0.98 (0.71–1.36)
No older adult family member at all	Reference		Reference		Reference		Reference	

OR: Odds ratio, aOR: Adjusted OR, CI: Confidence interval.

providers of older adult long-term care [18], [19] and are likely to have greater responsibility for domestic work. A previous study also reported that women are likely to have better knowledge about dementia [15], [20]. As a family caregiver, it is reasonable that women were more likely to find information about how to provide good care for their older adult family members. Thus, engagement with older family members may equip women with better knowledge about issues affecting older individuals, including dementia. In addition, professional workers usually achieve a certain levels of education which may influence their knowledge about dementia.

Communication and behavior

This subscale focuses on the psychological features of dementia and how people with dementia interact with the world. Communication and behavior could become challenging for an individual with dementia. Without appropriate support, social interaction with an individual with dementia might cause further maladaptation [21]. The current findings revealed that individuals aged 45–49 years old had 1.7-times more knowledge about the communication and behavior of individuals with dementia, and those who worked as private employees or entrepreneurs, or who were unemployed, had less knowledge about the communication and behavior of individuals with dementia. A person is considered to enter the pre-older adult age at 45 years [12]. At this stage, a person has begun to reach maturity and is preparing to enter middle age. Therefore, there may be a tendency for this age group to prepare for old age by gaining information related to aging, including dementia and related issues. However, we found that lower occupational levels (unemployed, private employees, and entrepreneurs) negatively influenced individuals' knowledge about communication and behavior. One can be assumed that occupational status is related to socioeconomic background, including educational attainment and social class, and education access is strongly correlated with a person's level of knowledge.

Care considerations

The current study revealed that female gender and professional occupation were significantly associated with the care and consideration subscale. This subscale describes symptoms that are relevant to the provision of care [22]. As well as being sources of care for older adults, women who are engaged in professional work commonly achieve higher levels of education and a higher socioeconomic level that allows them to develop a good understanding of care considerations for people with dementia. Being knowledgeable about dementia may reinforce traditional values about women being "natural" caregivers for their older parents [23]. Between 60% and 70% of all

family carers of people with dementia are women [24]. Similar to other countries, Indonesian female spouses, daughters, and daughters-in-law are more likely to take on care roles than their male counterparts. There is a common myth that women are better carers, and although there are certain personality traits may support such notions (i.e., nurturing), there is no conclusive evidence that women are better careers than men [24]. However, several studies have shown that women have better knowledge about dementia [10], [20], [23].

Risk factors and health promotion

This subscale describes information regarding the risk factors and health conditions associated with or mistaken for dementia. The current results revealed that being male and unemployed were associated with poor knowledge about risk factors and health promotion related to dementia. Conversely, being female and working as a professional were significantly associated with better knowledge about this subscale topic. The current results revealed variation in the level of knowledge about risk factors and health promotion based on occupation level. This finding supported a previous study conducted by Smith *et al.* (2014) in an Australian community sample, who reported that knowledge about dementia risk reduction was influenced by socioeconomic status [9]. Thus, sufficient educational background related to professional occupation appears to strongly influence individuals' understanding of the risks and health promotion factors for dementia.

Conclusion

The current study confirmed that sociodemographic factors, including gender, age, and occupation showed a significant association with knowledge about dementia. We assumed that the living arrangements would be associated with specific knowledge on dementia, but no significant association was observed. The results emphasize the importance of intensive public health awareness to improve public knowledge about dementia in Indonesia, specifically targeting men and older individuals, as well as those with lower occupational levels.

Public awareness program has been included as one of strategic plan in the National Strategic for Management of Alzheimer and Other Dementia Disease Toward Healthy and Productive Older [25], however, the content of the awareness program is limited to self-awareness and healthy life style for preventing dementia. The public health campaign to increase understanding of how to deal with individuals with dementia in a comprehensive manner need to be increased to

provide community-based support systems for people with dementia. Policymakers should recognize the gap in knowledge, particularly among those living with older adults, those with lower socioeconomic status, and male gender. The current findings can inform evidence-based policy recommendations in the development of a national campaign to educate the public about dementia in Indonesia.

Our study used a cross-sectional approach, precluding us from drawing causal conclusions from our findings. Second, the sample size in this study was relatively limited. Third, the data collection using online surveys depends on internet network access, which is not evenly distributed throughout Indonesia. Thus, the current findings may not represent the entire population of Indonesia.

Availability of data

The datasets generated and analyzed in this study are not publicly available because ethical guidelines prohibit researchers from providing research data to third-party individuals.

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