











Dementia knowledge of family caregivers in Indonesia: A cross-sectional survey study

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Abstract

Background: As the population ages, the prevalence of dementia in Indonesia is rapidly increasing. In Indonesia, dementia care is primarily provided by informal or family caregivers. However, there is limited information about these caregivers' understanding of dementia and the factors that may influence their knowledge. Given that family members are the primary source of dementia care in Indonesia, it is essential to understand their knowledge and identify any gaps to inform future educational interventions.

Objective: To explore the knowledge of dementia among Indonesian family caregivers and identify the sociodemographic factors associated with dementia knowledge.

Methods: A cross-sectional survey was conducted in 2022 with 200 family caregivers who were members of Alzheimer's Indonesia (ALZI) support groups. These caregivers received invitations via ALZI to complete a translated version of the Dementia Knowledge Assessment Scale (DKAS-I). Independent *t*-tests and ANOVAs were used to examine differences in dementia knowledge across various subgroups, such as gender, education, and age.

Results: Seventy-six family caregivers completed the DKAS-I (38% response rate). Respondents had an average age of 49 years, were mostly female, and the majority were children of people with dementia. Over two-thirds of the DKAS-I items were answered correctly by family caregivers, with the 'care considerations' domain scoring the highest. Age, relationship to the person with dementia (being a child), and prior dementia education were significantly correlated with higher dementia knowledge in our sample.

Conclusion: Family caregivers of people living with dementia across 10 Indonesian provinces who were members of dementia support groups demonstrated moderate dementia knowledge. Targeted education is needed to address gaps in knowledge about communication and behavioural changes in people with dementia and other areas related to quality of care. There is an opportunity for gerontological nurses with specialised dementia knowledge to lead educational initiatives for family caregivers to enhance their capacity. Future research should also investigate the dementia knowledge of caregivers in the general population, who may be older and less educated compared to the participants in this study.

Keywords

Indonesia; dementia; knowledge; family; informal caregivers; sociodemographic factors

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Background

Globally, almost 9 million people are aged 60 years and older (Prince et al., 2015). In lower-middle-income countries, the number of older people is expected to increase by 29% between 2015 and 2030 (Prince et al., 2015). Indonesia has the fourth largest population in the world, and commensurate with global aging, there are significant increases in the number of older people (World Population Review, 2023). As a result, the prevalence of dementia in Indonesia was approximately

one million in 2015 (ranked 9th globally), and it is estimated to increase by 2030 to almost two million people and just under four million by 2050 (Alzheimer's Disease International, 2014). Dementia is one of the leading causes of disability for older people worldwide (World Health Organisation, 2012). Individuals with dementia experience a progressive decline in cognitive and physical abilities, leading to an increasing need for assistance in key functional areas such as self-care, mobilisation, swallowing, and communication (Livingston et al., 2017; Mataqi & Aslanpour, 2020). In emerging economies

such as Indonesia, the costs associated with dementia care are expected to rise as informal and formal care arrangements continue to grow to meet the needs of this population (Alzheimer's Disease International, 2014). Caregivers (both formal and informal) are crucial to supporting people with dementia as the disease advances. In Indonesia, as in other Asian countries, family members are responsible for most of the care for a person with dementia (Putri et al., 2022). Research has shown that family members feel a religious and cultural obligation to provide care for loved ones with dementia (Hossain et al., 2020; Kristanti et al., 2018).

The capability of family members to provide care that adequately meets the complex needs of someone with dementia is related to a variety of factors. These factors include knowledge of the disease and prognosis (Holt Clemmensen et al., 2021; Hossain et al., 2020; Mataqi & Aslanpour, 2020; Robinson et al., 2014; Thompson et al., 2021), attitudes towards dementia (Herrmann et al., 2018; Hossain et al., 2020), knowledge of intervention strategies especially in the case of managing behavioural and psychological symptoms (Holt Clemmensen et al., 2021; Moore et al., 2013) and care skills such as how to manage continence and nutrition issues (Bressan et al., 2020). A lack of understanding about dementia and its impacts can lead to stigmatization, barriers to diagnosis and treatment, and reductions in the quality of life for people with dementia and their family caregivers (World Health Organisation, 2012).

While a few studies have highlighted a lack of knowledge about dementia in the general population in Indonesia (Mulyani & Saifullah, 2021; Nugraha et al., 2022; Suriastini et al., 2020), there has been very little research conducted specifically with family caregivers of people with dementia. A recent phenomenological study explored the experiences of 15 family caregivers in Indonesia regarding the barriers and supports that family encounter in their role (Widyastuti et al., 2023). One of the key barriers identified was inadequate knowledge and skills of family caregivers regarding dementia. Another study has suggested that family caregivers in the regencies of Yogyakarta, Indonesia, have a poor understanding of early symptoms of dementia and may consider it as a normal part of the aging process (Suriastini et al., 2020). Similar findings have been reported in other parts of Asia (Alzheimer's Disease International, 2014; Holt Clemmensen et al., 2021; Kristanti et al., 2018). Other Indonesian studies have focused on student nurses' knowledge of dementia (Sunaryo et al., 2020) and trained nurses' knowledge of dementia (Rahmi et al., 2021). Nugraha et al. (2022) examined the knowledge of dementia among middle-aged people in Indonesia and reported that female gender, younger age, and higher occupational status were associated with higher dementia knowledge.

Although the prevalence of dementia in Indonesia is expected to increase and family caregivers are the primary source of support, surprisingly, little is known about family caregivers' knowledge of dementia and what factors may influence this. Addressing this gap is crucial, as insights into caregivers' understanding of dementia can guide support and educational initiatives (Annear et al., 2017a). It may also help inform the nursing and medical workforce about targeting educational interventions to better support family caregivers. Therefore, this project aimed to explore i) Indonesian family

caregivers' understanding of dementia using a translated version of a dementia knowledge tool and ii) sociodemographic factors that may be related to dementia knowledge.

Methods

Study Design

This study used a cross-sectional survey design to measure the dementia knowledge of family caregivers across 10 Indonesian provinces.

Participants and Setting

Participants were family members of people living with dementia who identified themselves as the main caregiver and who were 18 years or older. Participants must have been able to access the Internet and the mobile application WhatsApp to access and complete an online survey to partake in this study. Convenience sampling was used to recruit participants from the Alzheimer's Indonesia (ALZI) Family Caregiver Networks. ALZI is a not-for-profit organization that aims to improve the quality of life for people living with dementia, their family, and caregivers through awareness raising, advocacy, and education (<https://alzi.or.id/>). ALZI comprises 16 chapters across 10 Indonesian provinces (North Sumatera, Riau, Jakarta, West Java, Central Java, Yogyakarta, East Java, Bali, West Nusa Tenggara and North Sulawesi).

Instrument

In this study, we chose to use the Dementia Knowledge Assessment Scale (DKAS) (Annear et al., 2017a) with permission from the authors. The DKAS is an English language tool that has been used with formal and informal caregivers in Australia (Annear et al., 2017a), Spain (Carnes et al., 2021), Japan (Annear et al., 2017b), and Taiwan (Hung et al., 2022). Across these studies, the tool has been found to have good psychometric properties. The original DKAS is a 25-item tool. Items are divided into four domains: 1) causes and characteristics, 2) communication and behaviour, 3) care considerations, and 4) risks and health promotion (Annear et al., 2017a). Five response options (false, probably false, don't know, probably true, true) are given a score of 0, 0, 0, 1, 2, respectively. The maximum correct score is 50, where a higher score indicates more correct answers. The DKAS has already been translated into an Indonesian version (DKAS-I) for use with Indonesian nursing students (Sunaryo et al., 2020). The initial translation followed Brislin's Model for translation, which involved a rigorous process of forward and backward instrument translation (Sunaryo et al., 2020). In this project, the DKAS-I underwent an additional panel review to ensure cross-cultural relevance to family caregivers of people with dementia. The expert panel comprised two neurologists, one general practitioner, five nursing academics/researchers, and two family caregivers. Based on the review, the team consensus was that no changes were necessary to the tool. In addition to the DKAS-I, demographic data were collected, which included age, relationship to the person with dementia, time spent each day caring for the person with dementia, length of time being a caregiver, the highest education level, and attendance at dementia education.

Data Collection

Participant recruitment occurred online in May 2022. At the time of this study, there were 1100 family caregivers registered with Alzheimer's Indonesia. The sample size for this study was calculated using data from [Mulyani and Saifullah \(2021\)](#), which investigated dementia knowledge among long-term care staff in Yogyakarta, Indonesia. There was no other demographically comparable cohort of family caregivers using the DKAS-I; hence, we used data from [Mulyani and Saifullah \(2021\)](#) on paid carers. In that study, the mean Dementia Knowledge Assessment Scale (DKAS-I) score was 28.86, with a standard deviation of 8.73. For this study, we aimed for a margin of error of 5% of the mean score. Using the standard formula for sample size calculation at a 95% confidence level and adjusting for a finite population size of 1,100, we determined that 125 participants were required.

Family caregivers who were members of ALZI were sent an invitation to participate via the mobile instant messaging service – WhatsApp. WhatsApp is widely used as a communication mode in Indonesia, and it is ALZI's preferred method of contact with its stakeholders. Each ALZI chapter has a dedicated WhatsApp group for family caregivers through which information and resources are regularly shared. A study invitation, containing a Participant Information Sheet in Indonesian and a link to the online survey was provided to family caregivers' WhatsApp groups in each ALZI chapter. Across the ALZI chapters, a total of 200 family caregivers were registered on the WhatsApp groups. All of these family caregivers were sent invitations to participate in the study. A total of 200 invitations were sent. Family caregivers were able to access the DKAS-I via a LimeSurvey link. Consent to participate in the study was deemed to have been received once a participant had indicated (by checking a box) that they had read and understood the information sheet and subsequently completed the survey. All data collected was anonymous. The online survey remained open for seven months. Data were then downloaded from the LimeSurvey and put into an Excel spreadsheet.

Data Analysis

Data analysis was conducted using IBM SPSS version 22.0. First, the data set was checked for missing data and outliers. There were 41 incomplete survey responses, where participants had filled in some or all of the demographic information but did not proceed to complete the DKAS-I. These data were removed from the analysis. Reverse-scored items (items 1, 3-5, 6-7, 9, 12-16, 19, 20) were recoded. The DKAS-I total score was calculated by summing individual item scores. The Cronbach's alpha coefficient was calculated for the DKAS-I. Demographic characteristics (e.g., age, gender, educational level) and the DKAS-I score were analysed using univariate analysis, i.e., means and standard deviations for continuous variables and frequency percentages for the categorical data. The DKAS-I scores had a normal distribution. Independent *t*-tests and ANOVAs were used to examine the differences in dementia knowledge across various subgroups, such as gender, education, and age (using mean age as a cut-off point for the groups). Due to the small sample size, the multivariate analysis did not proceed, and further investigation was warranted.

Ethical Considerations

This project was approved by the University of Tasmania Human Research Ethics Committee, approval number H24593. Participants could stop their participation by closing the survey link; however, they could not withdraw their responses after completing the survey, as their data remained anonymous. No personal information which can identify a person was collected in this survey.

Results

Participants Characteristics

Two hundred family caregivers were invited to participate in the survey, and 117 people responded. Among these responses, 41 people did not provide a complete demographic and DKAS data set and were subsequently excluded from the analysis. The incomplete survey may reflect unfamiliarity with the lime survey platform. Consequently, 76 complete surveys were subject to analysis, resulting in a response rate of 38%. While this sample size was smaller than that calculated, due to project timeframes and financial constraints, we were unable to continue further data collection. Of the respondents, only nine (12%) were male. The average age of respondents was 49 years (SD = 11.4), while the majority, 52 out of 76 (68%), were children of people with dementia. In terms of time spent caring for a person with dementia, over half (54%) of the caregivers reported spending between 1-5 years caring for the person with dementia. Specifically, 27% (20 out of 76) provided care for 1-3 years, and an equal percentage of 27% (20 out of 76) provided care for 3-5 years. Furthermore, 19% (14 out of 76) of the caregivers had been providing care for 5-8 years. The remaining caregivers either provided care for less than one year (15%, 11 out of 76) or eight years and more (13%, 10 out of 76). Forty-eight respondents (64%) reported having undertaken some form of dementia-related education. Among these, thirty-one respondents identified Alzheimer's Indonesia as the source of their learning, where they received dementia skills training, viewed webinars, or attended caregiver meetings. Two respondents indicated they had received education provided by Alzheimer's Disease International, and three respondents sourced information through other means, such as YouTube and online webinars.

Dementia Knowledge

The mean correct DKAS-I score (out of a possible 50) was 33 (SD = 7.37). The lowest domain score was in the communication and behaviour domain (see [Table 1](#)). Of the six items in this domain, four (14, 15,16,19) had a correct response rate of 50% or less (see [Table 2](#)). On individual item analysis, items answered correctly by 50% or less of the respondents were related to the treatment of behavioural and psychological symptoms (1), dementia and depression symptoms (10), communication with the person with advanced dementia (16,14), the life-limiting nature of dementia (7), vascular causes of dementia (6) the presentation of dementia symptoms (13) and the role of the environment in the care of the person with dementia (15). The only variables that were found to be significantly associated with higher DKAS-I scores were age, being a caregiver who was a child, and having undertaken dementia education (see [Table 3](#)). Respondents' education level was also associated with higher DKAS-I

scores; however, this finding was not significant at the 5% level and was borderline significant (Thiese et al., 2016). This borderline significance is likely an artefact of a smaller sample, and as such, we treat the level of education as a meaningful

predictor of DKAS-I scores here. The Cronbach's alpha for the DKAS-I was 0.78. This coefficient was lower when compared to other studies utilizing the same 25-item version ($\alpha = 0.85$ (Annear et al., 2017a); $\alpha = 0.82$ (Carnes et al., 2021).

Table 1 DKAS-I domain scores

DKAS-I Score	Min-Max	Mean	SD
Causes and characteristics (max score = 14); DKAS-I items: 1, 2, 3, 4, 5, 6, 7	0-14	8.92	3.10
Communication and behaviour (max score = 12); DKAS-I items: 14, 15, 16, 17, 18, 19	1-12	6.65	2.37
Care considerations (max score = 12); DKAS-I items: 20, 21, 22, 23, 24, 25	4-12	10.45	2.22
Risk and health promotion (max score = 12); DKAS-I items: 8, 9, 10, 11, 12, 13	2-12	7.47	2.65

Table 2 Percentage correct answers DKAS-I items (in order of % correct)

Item Number	Item	n	%
5	Planning for end-of-life care is generally not necessary following a diagnosis of dementia	69	90.8
25	Daily care for a person with advanced dementia is effective when it focuses on providing comfort	69	90.8
20	People experiencing dementia do not generally have problems making decisions	67	88.2
11	Exercise is generally beneficial for people experiencing dementia	66	86.8
23	People experiencing dementia often have difficulty in learning new skills	62	81.6
4	Dementia does not result from physical changes in the brain	60	78.9
22	People with advanced dementia may have difficulty speaking	58	76.3
21	Movement is generally affected in the later stages of dementia	54	71.1
24	Difficulty eating and drinking generally occurs in the later stages of dementia	54	71.1
1	Dementia is a normal part of the ageing process	54	71.1
8	Having high blood pressure increases a person's risk of developing dementia	52	68.4
2	Alzheimer's disease is the most common form of dementia	50	65.8
17	People experiencing advanced dementia often communicate through body language	50	65.8
3	People can recover from the most common forms of dementia	49	64.5
9	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia	48	63.2
12	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition	46	60.5
18	Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs	45	59.2
16	It is important to correct a person with dementia when they are confused	38	50.0
19	Medications are the most effective way of treating behavioural symptoms of dementia	35	46.1
10	Symptoms of depression can be mistaken for symptoms of dementia	34	44.7
14	It is impossible to communicate with a person who has advanced dementia	33	43.4
7	Most forms of dementia do not generally shorten a person's life	19	25.0
6	Blood vessel disease (vascular dementia) is the most common form of dementia	17	22.4
13	The sudden onset of cognitive problems is characteristic of common forms of dementia	8	10.5
15	A person experiencing advanced dementia will not generally respond to changes in their physical environment	8	10.5

Table 3 Demographics and difference in DKAS-I score

Variables	Subgroup (n)	DKAS-I Score	
		Mean (SD)	p-value
Gender [^]	Male (n = 9)	30.8 (10.8)	0.24
	Female (n = 67)	33.9 (6.81)	
Age [^]	Up to 50 (n = 45)	34.9 (7.1)	0.02*
	50 and above (n = 31)	31.3 (7.2)	
Relationship with the dementia patient#	Spouse (n = 14)	30.2 (8.67)	0.05*
	Child (n = 52)	34.5 (6.56)	
	Other (grandchildren, niece/nephew) (n = 10)	30.8 (7.36)	
Daily dementia care duration [^]	<8 hours (n = 39)	32.6 (6.53)	0.29
	≥8 hours (n = 37)	34.4 (8.15)	
Dementia care experience [^]	<3 year (n = 31)	32.3 (7.91)	0.28
	≥3years (n = 44)	34.1 (6.85)	
Level of education [^]	Bachelor's degree (n = 14)	30.2 (5.95)	0.06
	Postgraduate (n = 62)	34.2(7.49)	
Dementia education [^]	Yes (n = 48)	34.9 (7.35)	0.04*
	No (n = 27)	31.2 (6.91)	

Note: *p < 0.05 | [^]Independent t-test | #ANOVA test

Discussion

This is the first paper that has reported quantitatively on dementia knowledge among Indonesian family caregivers. The dementia knowledge score of our sample reflects correct answers for over two-thirds of the items. Using the criteria offered by Eccleston et al. (2021) that a score of more than 25 on the DKAS is considered indicative of moderate dementia knowledge, with a mean score of 33 (SD = 7.37) out of a possible 50 and all subgroups' mean scores >25, our sample demonstrated a good level of dementia knowledge. A number of demographic variables were significantly correlated with higher dementia knowledge in our sample. These variables included age, relationship to the person with dementia (being a child), and exposure to dementia education.

Respondents aged 18-50 years and were a child of the person with dementia had significantly higher dementia knowledge scores. Younger and middle-aged people, usually children, are the mainstay of family-based care in Asian countries, and, as such, they may be more likely to locate information about dementia (Liu et al., 2019). Furthermore, research with family caregivers of older people with chronic diseases in China has shown that younger age is a predictor for e-health literacy (Soleimaninejad et al., 2019). Indonesian research on health literacy also indicates that younger individuals may possess better skills in terms of locating and appraising health-related information online (Malini et al., 2023).

In our sample, dementia education was associated with higher DKAS scores, consistent with the findings of Eccleston et al. (2021). Sixty-three per cent of our sample had previously undertaken some type of education about dementia, and at least half of these people had accessed education offered by Alzheimer's Indonesia (ALZI). This is perhaps not surprising given that participants were drawn from the ALZI membership. A key goal of ALZI is to provide education (via regular webinars, short information videos on social media, and caregiver training) and advocacy services. Our findings suggest that being affiliated with a support organization or peak body that provides caregiver education may positively impact dementia knowledge. Widyastuti et al. (2023) have also reported that Indonesian family caregivers, in their qualitative study, considered education provided by non-governmental organizations (NGOs) to play a crucial role in improving their knowledge and skills about dementia. It is, however, essential to note that the mean score of 35 (out of a max of 50) for those respondents in our study who had accessed dementia education was significantly lower than 45, the cut-off point proposed by Eccleston et al. (2019) to indicate a high level of dementia knowledge in a population that had not undertaken extensive education. These findings highlight further room for knowledge improvement in this population. Future larger-scale research exploring how NGOs can work with Government and health care providers to build the capability and capacity of informal caregivers is urgently needed.

Our findings show the borderline significance of educational attainment on dementia knowledge scores. This finding is likely due to the small sample size in this survey (Thiese et al., 2016) and the homogenous nature of education (all respondents had undergraduate or postgraduate degrees).

Those family caregivers with post-graduate education did have higher overall knowledge scores, and the borderline significance indicates that educational attainment, alongside age and the relationship to the person with dementia, is likely to influence dementia knowledge. A positive relationship between prior educational attainment and dementia knowledge has been previously reported in research using the DKAS (Eccleston et al., 2019; Eccleston et al., 2021; Liu et al., 2020). In a Korean study, a higher level of formal education was associated with higher dementia knowledge (Lee et al., 2016). Indeed, health literacy is strongly correlated with educational attainment (Lorini et al., 2018), and higher education has been associated with improved health literacy related to chronic disease (Liu et al., 2020). In 2021, only 13% of Indonesians between the ages of 25 and 64 years old are reported to have undertaken tertiary education (OECD, 2022); therefore, it is likely that our findings may have been different if we had surveyed a broader cross-section of the population.

Our findings also revealed that individuals who had been family caregivers for a longer period tended to have higher knowledge scores, although this finding did not reach statistical significance. Previous research has identified that experience related to caring for a person with dementia is associated with higher dementia knowledge, as caregivers likely engage in more experiential learning and more opportunities to seek and access information from lay or formal sources (Eccleston et al., 2019). However, another study investigating the suitability of the DKAS with informal caregivers in Singapore found that the duration of caregiving did not significantly impact dementia knowledge (Tan et al., 2021). Further research in this area with a larger sample of Indonesian caregivers is needed to better understand the impact of caregiving tenure – given that the majority of care for people with dementia in Indonesia is provided by family and close kin. This link is important because there is a possibility that as the time spent providing care increases, so do the opportunities to support caregivers in effectively accessing, appraising, and using dementia-related information (Kimzey et al., 2022). This, in turn, can help build their strengths and abilities to better meet the needs of the person with dementia. Moreover, exposure to someone with dementia has been found to be associated with lower stigma towards people with this disease (Cheng et al., 2011), which in turn can influence information-seeking behaviour.

In relation to the DKAS domain knowledge scores, the communication and behaviour domain exhibited the lowest score. Similar deficits in caregiver knowledge of communication difficulties and changed behavioural presentations have been presented elsewhere (Annear et al., 2017a; Carnes et al., 2021; Hossain et al., 2020). Several items within this domain related to effective communication strategies and behavioural management techniques (DKAS items 14,15,16) were answered correctly by 50% or less of the respondents. This finding aligns with earlier research that indicated informal caregivers often lack knowledge about behavioural changes in individuals with dementia (Hu et al., 2023; Zwaanswijk et al., 2013) and require support to understand communication needs and how to manage them (Soong et al., 2020). Given that behavioural factors and communication changes have been the frequently cited cause

of caregiver burden (Chiao et al., 2015), our findings emphasise the need for education and support mechanisms to assist caregivers in navigating these complex changes.

Additionally, upon further item analysis, it was evident that family caregivers exhibited particularly poor knowledge concerning dementia as a life-limiting condition (DKAS item 7), a finding that has been reported elsewhere (Andrews et al., 2017). However, their knowledge about the importance of planning for end-of-life care was high (DKAS item 5). One plausible explanation for these seemingly contradictory findings is that education about care planning may receive more attention and available educational resources compared to content related to dementia being a cause of death due to the stigma associated with dying with dementia (Harrison et al., 2019). These findings suggest a need for targeted education efforts about the life-limiting nature of dementia and the dying course of dementia. This recommendation becomes all the more critical considering the projected four-fold increase in the number of people with dementia in Indonesia by 2050. Addressing the gaps in knowledge through tailored educational interventions could significantly enhance family caregivers' understanding and preparedness for managing dementia as a life-limiting condition and planning for end-of-life care effectively.

Limitations

Our findings need to be interpreted with caution for a number of reasons. Firstly, this study used a cross-sectional design; thus, the relationships between demographic variables and dementia knowledge should be interpreted as associations rather than causal relationships. Secondly, future research with Indonesian caregivers will need to include a larger and more diverse caregiver population to enhance the generalizability of the findings. This work should consist of the dementia knowledge of caregivers not affiliated with ALZI or another support group, as this may yield different findings. Furthermore, a more demographically diverse population with a larger sample size would enable a more comprehensive analysis of the DKAS-I psychometric properties. Further testing of the DKAS-I is warranted to enhance the Cronbach's alpha coefficient. Factor analysis conducted in Asian populations, such as Japan (Annear et al., 2017b) and Taiwan (Hung et al., 2022), suggested the possibility of reducing some items for a stronger factor structure and a higher reliability coefficient. This could involve refining the questionnaire based on feedback and insights from a larger and more heterogeneous participant pool, ultimately contributing to the improvement and robustness of the scale's measurement properties. Finally, the methods of survey distribution may also need to be revised, given that 35% of potential participants only completed the demographic section of the survey and did not go on to complete the DKAS-I. An alternative survey platform may need to be considered. Moreover, online data collection depends on internet network access, and therefore, people in more rural areas, where access is more limited, may not have been captured in our study.

Implications of this Study for Nursing Practice and Health Care Policy

While family caregivers in this study demonstrated moderate dementia knowledge, our findings indicate a need for targeted

education that addresses communication and behavioural management strategies, in addition to less well-understood aspects of the disease trajectory, such as its life-limiting nature. Such education goes beyond public awareness campaigns, albeit addressing the general public's knowledge is essential for Indonesia (Mulyani et al., 2019). Enhancing community-based support where gerontological nurses with specialist knowledge about dementia can provide targeted education to family caregivers could build and extend existing capacity within caregiver cohorts. This will require additional investment by the Government to develop such a highly skilled primary care nursing workforce. However, with nurses making up the majority of healthcare professionals in Indonesia (Efendi et al., 2022), policymakers should consider how nurse-led initiatives can support informal caregivers who provide the bulk of dementia care in the country. Such initiatives would ideally work in collaboration with other growing social care dementia programs in Indonesia, such as the ALZI's Dementia Care Navigator program (Alzheimer's Disease International, 2014), which provides pre and post-diagnostic support for people living with dementia and their family caregivers.

Conclusion

This study investigated dementia knowledge among Indonesian family caregivers using the DKAS-I. This study revealed a moderate level of dementia knowledge held by caregivers who were members of caregiver support groups associated with ALZI. Caregivers who were younger, a child of the person with dementia, and had prior access to dementia education were found to have significantly higher dementia knowledge. However, our findings also highlight that there is room for improvement in the overall dementia knowledge of our sample. Our data suggests the need for more targeted education/interventions with respect to communication and behavioural changes, as well as dementia being a life-limiting condition. Moreover, there is also a need for further investigation into dementia knowledge of caregivers who may be older and more educationally disadvantaged compared to our cohort of participants.

Declaration of Conflicting Interest

Michael Dirk, DY Suharya, Yuda Turana, Sri Mulyani, Azam Saifullah, and Tari Sani are members of Alzheimer's Indonesia.

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Authors' Contributions

SA was responsible for the conception of the research proposal, planning ethical approval, data collection, peer review of data analysis, data interpretation, and drafting of the manuscript. DYS, TS, MD, KE, and KK made substantial contributions to the conception and planning of the project, as well as critical revision of the manuscript. SM, AZS, MD, YT, NS, KK, and CE made substantial contributions to data collection, data analysis, and critical review of the manuscript. TTHD made substantial contributions to data analysis, drafting the manuscript and critical review of the manuscript. All authors approved the final manuscript.

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Data Availability

The data set generated and analysed during the current study is available from the corresponding authors (SA) upon reasonable request.

Declaration of Use of AI in Scientific Writing

There is nothing to disclose.

References

Alzheimer's Disease International. (2014). *Dementia in the Asia Pacific Region*. <https://www.alzint.org/u/Dementia-Asia-Pacific-2014.pdf>

Andrews, S., McInerney, F., Toye, C., Parkinson, C.-A., & Robinson, A. (2017). Knowledge of Dementia: Do family members understand dementia as a terminal condition? *Dementia*, 16(5), 556-575. <https://doi.org/10.1177/1471301215605630>

Annear, M. J., Otani, J., & Li, J. (2017b). Japanese-language Dementia Knowledge Assessment Scale: Psychometric performance, and health student and professional understanding. *Geriatrics & Gerontology International*, 17(10), 1746-1751. <https://doi.org/10.1111/ggi.12911>

Annear, M. J., Toye, C., Elliott, K.-E. J., McInerney, F., Eccleston, C., & Robinson, A. (2017a). Dementia knowledge assessment scale (DKAS): Confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, 17, 168. <https://doi.org/10.1186/s12877-017-0552-y>

Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, 28(6), 1942-1960. <https://doi.org/10.1111/hsc.13048>

Carnes, A., Barallat-Gimeno, E., Galvan, A., Lara, B., Lladó, A., Contador-Muñana, J., Vega-Rodríguez, A., Escobar, M. A., & Piñol-Ripoll, G. (2021). Spanish-dementia knowledge assessment scale (DKAS-S): Psychometric properties and validation. *BMC Geriatrics*, 21, 302. <https://doi.org/10.1186/s12877-021-02230-w>

Cheng, S.-T., Lam, L. C. W., Chan, L. C. K., Law, A. C. B., Fung, A. W. T., Chan, W.-c., Tam, C. W. C., & Chan, W.-m. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *International*

Psychogeriatrics, 23(9), 1433-1441. <https://doi.org/10.1017/S1041610211000834>

Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62(3), 340-350. <https://doi.org/10.1111/inr.12194>

Eccleston, C., Doherty, K., Bindoff, A., Robinson, A., Vickers, J., & McInerney, F. (2019). Building dementia knowledge globally through the understanding dementia Massive Open Online Course (MOOC). *npj Science of Learning*, 4(1), 3. <https://doi.org/10.1038/s41539-019-0042-4>

Eccleston, C. E., Courtney-Pratt, H., McInerney, F., Johnstone, A., & Doherty, K. (2021). Predictors of dementia knowledge in a rural general public sample. *Australian Journal of Rural Health*, 29(4), 530-537. <https://doi.org/10.1111/ajr.12777>

Efendi, F., Aurizki, G. E., Auwalin, I., Kurniati, A., Astari, L. D., Puspitasari, I. T., & Chong, M. C. (2022). The paradox of surplus and shortage: A policy analysis of nursing labor markets in Indonesia. *Journal of Multidisciplinary Healthcare*, 15, 627-639. <https://doi.org/10.2147/JMDH.S354400>

Harrison, K. L., Hunt, L. J., Ritchie, C. S., & Yaffe, K. (2019). Dying with dementia: Under-recognized and stigmatized. *Journal of the American Geriatrics Society*, 67(8), 1548-1551. <https://doi.org/10.1111%2Fjgs.15895>

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 26(3), 316-331. <https://doi.org/10.1016/j.jagp.2017.09.006>

Holt Clemmensen, T., Hein Lauridsen, H., Andersen-Ranberg, K., & Kaae Kristensen, H. (2021). Informal carers' support needs when caring for a person with dementia—A scoping literature review. *Scandinavian Journal of Caring Sciences*, 35(3), 685-700. <https://doi.org/10.1111/scs.12898>

Hossain, M., Crossland, J., Stores, R., Dewey, A., & Hakak, Y. (2020). Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. *Dementia*, 19(5), 1441-1473. <https://doi.org/10.1177/1471301218800641>

Hu, R., Zhang, F., Zhang, Y., Lai, B., Ma, W., Xu, X., Ye, H., Lv, Z., Chan, C., & Tao, Q. (2023). Development and validation of a Knowledge Scale About the Behavioral and Psychological Symptoms of Dementia (KS-BPSD) among Chinese formal caregivers. *Clinical Gerontologist*, 46(4), 599-607. <https://doi.org/10.1080/07317115.2022.2111290>

Hung, S.-P., Liao, Y.-H., Eccleston, C., & Ku, L.-J. E. (2022). Developing a shortened version of the dementia knowledge assessment scale (DKAS-TC) with a sample in Taiwan: An item response theory approach. *BMC Geriatrics*, 22, 886. <https://doi.org/10.1186/s12877-022-03596-1>

Kimzey, M., Howe, C. J., Martin, C., McLarty, J., & Baucham, R. (2022). Development of health literacy in persons and caregivers living with dementia: A qualitative directed content analysis. *Dementia*, 21(2), 540-555. <https://doi.org/10.1177/14713012211049691>

Kristanti, M. S., Engels, Y., Effendy, C., Utarini, A., & Vernooij-Dassen, M. (2018). Comparison of the lived experiences of family caregivers of patients with dementia and of patients with cancer in Indonesia. *International Psychogeriatrics*, 30(6), 903-914. <https://doi.org/10.1017/S1041610217001508>

Lee, J.-Y., Park, S., Kim, K. W., Kwon, J. E., Park, J. H., Kim, M. D., Kim, B.-J., Kim, J. L., Moon, S. W., & Bae, J. N. (2016). Differences in knowledge of dementia among older adults with normal cognition, mild cognitive impairment, and dementia: A representative nationwide sample of Korean elders. *Archives of Gerontology and Geriatrics*, 66, 82-88. <https://doi.org/10.1016/j.archger.2016.04.013>

Liu, D., Cheng, G., An, L., Gan, X., Wu, Y., Zhang, B., Hu, S., Zeng, Y., & Wu, L. (2019). Public knowledge about dementia in China: A national WeChat-based survey. *International Journal of Environmental Research and Public Health*, 16(21), 4231. <https://doi.org/10.3390/ijerph16214231>

Liu, L., Qian, X., Chen, Z., & He, T. (2020). Health literacy and its effect on chronic disease prevention: Evidence from China's data. *BMC Public Health*, 20, 690. <https://doi.org/10.1186/s12889-020-08804-4>

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., & Cohen-Mansfield, J.

- (2017). Dementia prevention, intervention, and care. *The Lancet*, 390(10113), 2673-2734. [https://doi.org/10.1016/S0140-6736\(17\)31363-6](https://doi.org/10.1016/S0140-6736(17)31363-6)
- Lorini, C., Ierardi, F., Bachini, L., Donzellini, M., Gemmi, F., & Bonaccorsi, G. (2018). The antecedents and consequences of health literacy in an ecological perspective: Results from an experimental analysis. *International Journal of Environmental Research and Public Health*, 15(4), 798. <https://doi.org/10.3390/ijerph15040798>
- Malini, H., Efendi, F., Kadar, K. S., Lenggogeni, D. P., & Sari, Y. P. (2023). Health literacy and associated factors among patients with chronic diseases in Indonesia. *Journal of Public Health*, 1-8. <https://doi.org/10.1007/s10389-023-02035-8>
- Mataqi, M., & Aslanpour, Z. (2020). Factors influencing palliative care in advanced dementia: A systematic review. *BMJ Supportive & Palliative Care*, 10(2), 145-156. <https://doi.org/10.1136/bmjspcare-2018-001692>
- Moore, K., Ozanne, E., Ames, D., & Dow, B. (2013). How do family carers respond to behavioral and psychological symptoms of dementia? *International Psychogeriatrics*, 25(5), 743-753. <https://doi.org/10.1017/S1041610213000070>
- Mulyani, S., Artanti, E., & Saifullah, A. (2019). Knowledge and attitudes towards people with dementia among general population in Yogyakarta. The Third International Conference on Sustainable Innovation 2019 – Health Science and Nursing (IcoSIHSN 2019), Yogyakarta, Indonesia.
- Mulyani, S., & Saifullah, A. D. (2021). Effect of dementia training on knowledge and attitude among long-term care staff in Yogyakarta, Indonesia. *Open Access Macedonian Journal of Medical Sciences*, 9(E), 592-597. <https://doi.org/10.3889/oamjms.2021.6392>
- Nugraha, S., Tondokoro, T., Susilowati, I. H., Hasiholan, B. P., Alimoeso, S., Rahardjo, T. B. W., Takagi, K., & Wada, K. (2022). Knowledge about dementia and its associated factors: Study among the middle-aged population in Indonesia. *Open Access Macedonian Journal of Medical Sciences*, 10(E), 783-789. <https://doi.org/10.3889/oamjms.2022.8892>
- OECD. (2022). *Education at a glance: OECD Indicators*. https://www.oecd-ilibrary.org/education/educational-attainment-of-25-64-year-olds-2021_5e744105-en
- Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. <https://www.alzint.org/u/WorldAlzheimerReport2015.pdf>
- Putri, Y. S. E., Putra, I. G. N. E., Falahaini, A., & Wardani, I. Y. (2022). Factors associated with caregiver burden in caregivers of older patients with dementia in Indonesia. *International Journal of Environmental Research and Public Health*, 19(19), 12437. <https://doi.org/10.3390/ijerph191912437>
- Rahmi, U., Andriyani, S., Supriatin, E., & Rahmayati, E. (2021). Nurses' knowledge about dementia care: A cross-sectional survey. *Malaysian Journal of Medicine & Health Sciences*, 17(Supp 14), 60-65.
- Robinson, A., Eccleston, C., Annear, M., Elliott, K.-E., Andrews, S., Stirling, C., Ashby, M., Donohue, C., Banks, S., & Toye, C. (2014). Who knows, who cares? Dementia knowledge among nurses, care workers, and family members of people living with dementia. *Journal of Palliative Care*, 30(3), 158-165. <https://doi.org/10.1177/082585971403000305>
- Soleimaninejad, A., Valizadeh-Haghi, S., & Rahmatizadeh, S. (2019). Assessing the eHealth literacy skills of family caregivers of medically ill elderly. *Online Journal of Public Health Informatics*, 11(2), e62589. <https://doi.org/10.5210/ojphi.v11i2.10149>
- Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Tudor Car, L. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: A scoping review. *BMC Geriatrics*, 20, 61. <https://doi.org/10.1186/s12877-020-1454-y>
- Sunaryo, S. R. A., Saifullah, A. D., & Mulyani, S. (2020). Knowledge and attitudes toward people with dementia among nursing students in Yogyakarta, Indonesia. *Belitung Nursing Journal*, 6(6), 196-202. <https://doi.org/10.33546/bnj.1178>
- Suriastini, N. W., Turana, Y., Supraptilah, B., Wicaksono, T. Y., & Mulyanto, E. D. (2020). Prevalence and risk factors of dementia and caregiver's knowledge of the early symptoms of alzheimer's disease. *Aging Medicine and Healthcare*, 11(2), 60-66. <https://doi.org/10.33879/amh.2020.065-1811.032>
- Tan, G. T. H., Yuan, Q., Devi, F., Wang, P., Ng, L. L., Goveas, R., Chong, S. A., & Subramaniam, M. (2021). Dementia knowledge and its demographic correlates amongst informal dementia caregivers in Singapore. *Ageing & Mental Health*, 25(5), 864-872. <https://doi.org/10.1080/13607863.2020.1740914>
- Thiese, M. S., Ronna, B., & Ott, U. (2016). P value interpretations and considerations. *Journal of Thoracic Disease*, 8(9), E928-E931. <https://doi.org/10.21037%2Fjtd.2016.08.16>
- Thompson, G., Hack, T., Rodger, K., St. John, P., Chochinov, H., & McClement, S. (2021). Clarifying the information and support needs of family caregivers of nursing home residents with advancing dementia. *Dementia*, 20(4), 1250-1269. <https://doi.org/10.1177/1471301220927617>
- Widyastuti, R. H., Sahar, J., Rekawati, E., & Kekalih, A. (2023). Barriers and support for family caregivers in caring for older adults with dementia: A qualitative study in Indonesia. *Nurse Media Journal of Nursing*, 13(2), 188-201. <https://doi.org/10.14710/nmjn.v13i2.55729>
- World Health Organisation. (2012). *Dementia: A public health priority*. <https://www.alzint.org/resource/dementia-a-public-health-priority/>
- World Population Review. (2023). *Total population by country 2023*. <https://worldpopulationreview.com/countries>
- Zwaanswijk, M., Peeters, J. M., Van Beek, A. P. A., Meerveld, J. H. C. M., & Francke, A. L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: A questionnaire survey. *The Open Nursing Journal*, 7, 6-13. <https://doi.org/10.2174%2F1874434601307010006>

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