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## **Dementia literacy in West Pacific Countries: A mixed-methods study**

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## ABSTRACT

**Background:** The prevalence of dementia is expanding rapidly in low- and middle-income countries (LMIC) but there is limited information on dementia literacy. The objectives of this study are to examine the levels of knowledge about dementia and attitude towards dementia, to identify from whom LMIC citizens would seek help, and the citizens' characteristics that are predictive of positive attitudes towards dementia.

**Methods:** This mixed-methods study using a quantitative survey and qualitative focus group interviews was conducted in three West Pacific countries (Cambodia, the Philippines and Fiji). For the survey, the scales used included the 30-item Alzheimer's Disease Knowledge Scale (ADKS), the 20-item Dementia Attitude Scale and the listed sources of help-seeking for dementia. For the focus groups interviews, a vignette about dementia was used to initiate the discussion about the knowledge, attitudes and views on help seeking for dementia.

**Results:** The ADKS mean total score ranged from 16.48 to 16.77 (SD 2.28-3.22) in the three countries. Some misconceptions of the causes of dementia were related to religious and cultural beliefs. DAS mean total score ranged from 92.95 to 93.68 (SD 13.52 – 15.84). More than half of the citizens in Cambodia (58.7%), the Philippines (65.9%) and one-third of the citizens in Fiji (34.7%) would seek help from family. Another one-quarter of the citizens in Fiji (27.3%) and one-tenth of the citizens in Cambodia (9.3%) and the Philippines (9.1%) would seek help from religious figures. Qualitative data also showed that family members were the major source of help in dementia while village leaders and religious figures were the other sources of help. Controlling demographics, ADKS total score was significantly associated with DAS total score ( $B=1.156$ ,  $SE=0.247$ ,  $p<0.001$ ) in the three countries. Country-specific predictors of positive

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attitudes towards dementia were found: knowledge about risk factors (B=2.550, SE=1.001, p=0.012) in Cambodia; education level (B=6.490, SE=1.833, p=0.001), knowledge about assessment/diagnosis (B=3.536, SE=1.294, p=0.007) and disease progression (B=2.595, SE=1.170, p=0.028) in the Philippines; and knowledge about life impact (B=6.374, SE=1.614, p<0.001) in Fiji.

**Conclusions:** The results of this study contributed to our understanding of dementia literacy in three LMIC in the Western Pacific region. Involvement of family members, religious leaders and village leaders in dementia education could enhance the recognition of dementia and promote the supports to this illness in these countries. To build up positive attitudes towards dementia, public education should target for specific kinds of dementia knowledge in different countries.

**Keywords:** dementia, health literacy, focus group interviews, knowledge, attitudes, religion

Word count: 396 words

## Introduction

The World Alzheimer's Report (Alzheimer's Disease International, 2015) has estimated that the number of people living with dementia in low- and middle-income countries (LMIC) will increase by 223-264% between 2015 and 2050. More research on dementia is therefore needed in these LMIC because an estimated two-thirds of the world's persons with dementia live in these countries (Prince, 2009). The present study utilized a mixed-methods design to generate an in-depth understanding of dementia knowledge, attitudes, and help-seeking behaviors in three LMIC countries in the Western Pacific region - Cambodian, Philippines, and Fiji.

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Dementia literacy is defined as “*knowledge and beliefs regarding dementia that aid recognition, management or prevention*” (Low and Anstey, 2009, p. 43). To assess dementia literacy, knowledge and attitudes towards dementia are measured. It has been suggested that higher dementia literacy will enable risk reduction, early diagnosis and improved management of dementia (Cahill et al., 2015; Low & Anstey, 2009; Smith et al., 2014). The public often have low literacy about dementia (Blay et al. 2008; Anderson et al., 2009), which poses a significant barrier to symptom recognition and treatment (Liu et al., 2008).

Increasing dementia knowledge and overcoming stigma through strategic communication and social mobilization are the crucial steps in breaking down barriers and strengthening local mental health programmes (WHO, 2008). However, these strategies must be designed with consideration of the local norms and contexts in order to generate the greatest impact. Currently, most of the previous studies in dementia literacy have been conducted in developed countries such as Australia (Low & Anstey, 2009), USA (Anderson et al., 2009) and Japan (Aihara et al., 2016). Thus, a knowledge gap exists in understanding citizens’ dementia literacy (that is, their knowledge about dementia and their attitudes towards persons with dementia) in LMIC. Understanding dementia literacy in the Western Pacific Region is the essential first step in designing an effective public health approach in the region.

Proposed by Low & Anstey (2009), dementia literacy should cover three perspectives: knowledge about dementia, attitudes towards dementia, and help seeking. Nonetheless, most of the previous studies did not cover all these perspectives, only focused on dementia knowledge (Lee & Woo, 2015; Low & Anstey, 2009). Only a recent study (Zhang et al., 2017) extended its work to the assessment of intention of treatment in dementia. Thus, there is a huge

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knowledge gap in dementia literacy, particularly how dementia knowledge is related to attitudes towards dementia and whether citizens have any idea of the source of help seeking when their family members or friends are suspected dementia. The objectives of this study were: (1) to examine the levels of knowledge about dementia in the selected countries (Cambodia; the Philippines; Fiji); (2) to assess the citizens' attitudes towards dementia; (3) to identify the sources of help seeking in dementia, and (4) to identify the relationship between dementia knowledge and positive attitudes towards dementia.

## **Methods**

### **Study Design**

This is a mixed-methods study with both quantitative (a cross-sectional survey) and qualitative (focus group interviews) components. A survey was completed by the citizens of these three countries, and two focus group interviews were conducted in each country to generate a context-specific understandings of dementia literacy within the local LMIC setting.

### **Sampling and subjects**

Convenience sampling was used to recruit the participants for both the survey and the focus group interviews. Inclusion criteria of eligible subjects in this study were: 1) urban adults and 2) aged 18 years or above. Subjects were identified by trained local data collectors from non-clinical settings, such as market places, parks, shopping malls, restaurants, villages, local community clubs, churches, and universities. This sampling strategy intended to obtain a broadly representative sample of people from different ages, genders and social classes in these countries.

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### **Study setting**

Data collection was conducted from November 2016 to May 2017 in urban areas and in semi-urban communities of Cambodia (Phnom Penh, Kandal Province), Philippines (Manila, Quezon and Caloocan City), and Fiji (Suva). The countries were chosen as the targeted investigation sites due to their differences in ethnic, religious, and socioeconomic composition within the Western Pacific region. The recruitment sites within each country were chosen in consultation with the local implementing partners in order to maximize the numbers of respondents and obtain a diverse sample of people from different age ranges, genders, and social classes. The local implementing partners included university research teams and/or representatives from the ministry of health in each country.

### **Data collection**

Prior to the commencement of study, the research team members provided research training workshops to the local data collectors, covering criteria of subject recruitment, strategies for recruitment, how to obtain informed consent, how to collect quantitative and qualitative data, and data entry. The cross-sectional survey and the focus groups were conducted concurrently. The local data collector explained the research objectives and procedures to the potential participants and made clear that the participation to this study was entirely voluntary. Written consent was obtained from the participants before the start of the focus group interviews. In each country, we aimed to recruit a minimum sample of 150 survey participants and 6-8 participants for each focus group interview. Two focus group interviews were arranged in each country. Ethical approval to conduct the study was obtained from the funding source (WHO), the Ministry of Health in each participating country, and the Human Subject Ethics Subcommittee of The Hong Kong Polytechnic University.

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## Measures

### *Quantitative measures*

The quantitative survey consisted of four parts: demographics, dementia knowledge, attitudes towards persons with dementia, and sources of dementia help seeking. The survey was translated into relevant language by the local project team members in Cambodia, and then back-translated to the English version, according to the WHO guidelines. Possible misinterpretation of items due to local practices or beliefs was identified and clarified before the study commenced. Demographic questions were about gender, age, employment status, highest academic qualification, accommodation, marital status, number of people living in the same household, types of chronic illnesses, and having personal contact with people experiencing dementia.

The Alzheimer's Disease Knowledge Scale (ADKS) was used to measure respondents' knowledge about dementia. The ADKS is a 30-item scale with true/false questions that assess knowledge with respect to the characteristics of dementia, with seven subscales including assessment and diagnosis, caregiving, life impact, disease progression, risk factors, symptoms, and treatment and management (Carpenter et al., 2009). The ADKS has demonstrated good internal consistency ( $\alpha = 0.71$ ) with adequate test-retest reliability (reliability coefficient = 0.81,  $p < 0.001$ ) in the general population with diverse ages (Carpenter et al., 2009). A higher score denotes higher knowledge about dementia.

The Dementia Attitude Scale (DAS) was used to determine the attitudes of respondents towards persons with dementia. The 20-items 7-point Likert scale (from 1 strongly disagree to 7

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strongly agree) has total-scale Cronbach's alphas ranging from 0.83–0.85 in college students and nursing students (O'Connor & McFadden, 2010). Evidence for convergent validity was promising, as the DAS correlated significantly with scales that measured ageism and attitudes toward disabilities (range of correlations = 0.44–0.55; mean correlation = 0.50) (O'Connor & McFadden, 2010). Scores for items 3, 4, 5, 7, 9 and 10 were reversed. The total score of DAS was the sum of all items: the higher the score, the more positive attitude towards persons with dementia. The DAS can be divided into two subscales, with the first 10 items measuring social comfort and the last 10 items measuring dementia knowledge.

Participants were also asked to identify three sources which they would approach (could be professionals or non-professionals) if they (or someone they knew) had signs of dementia. The listed sources of help seeking were compiled and categorized in the analysis. Dummy variables were created for the five sources: health care professionals, family, friends, religious figures and neighbors. For any indication of a particular source of help (for example, health care professionals) among the three indicated sources, 1 is given to this dummy variable. If there is no indication of this source, zero is given.

### **Qualitative interviews**

Focus group interviews were conducted to generate a context-specific understanding of dementia literacy within the local LMIC setting, trying to capture a deeper understanding about participants' perceptions of dementia, their attitudes towards persons with dementia, and the experiences they had when they tried to get access to dementia information. The local data collectors identified the participants who were willing and able to share their views and experiences in relation to the study topic. Each focus group was led by two trained facilitators



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selected by the local implementing partners. A case vignette about dementia was used to initiate discussion and explore participants' knowledge, attitudes, and views on help seeking for dementia. Use of a vignette helped to ensure that all participants focused their opinions to the same topic, although their perceptions and views of the topic may vary depending on their own beliefs and life experiences. Local implementing partners were free to modify the vignette script to enhance its cultural and contextual relevance. Guiding questions were used to stimulate the participants to discuss issues in relation to dementia. For example: Can you think of what a person with dementia may look like in your community? If you suspect that someone you know may have dementia, how would you approach this person? Who would you get involved or seek help from? Where would you seek information to learn more about this illness? All focus group interviews lasted between 60 to 90 minutes. At the end of the interviews, participants were asked to complete a demographic form.

### **Data analysis**

Quantitative and qualitative data were collected in parallel, analyzed independently, and then triangulated in the interpretation and discussion to generate a deeper understanding of the research topic (Creswell et al., 2011). Quantitative survey data were analyzed using IBM SPSS Statistical package version 23. Demographic data was described for each country. Chi-square tests were used to compare the demographics of the respondents among the three countries. Descriptive analysis (including mean, standard deviation, frequency and percentage) was performed in ADKS, DAS, and the sources of help seeking in dementia. Logistic regression was performed to assess the relationship between ADKS total score and DAS total score in these three countries, controlling the demographics. Further assessment was made on the factors associated with DAS total in each country by using logistic regressions with stepwise

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backward elimination. Demographics and the mean of the ADKS subscales were put into these regression models. Variables with level of significance of 0.10 were kept in the models if the models fit well. In the final model, variables with p-value <0.05 were considered as the predictors of positive attitudes towards dementia in each country.

Focus group interviews were audio-recorded and transcribed verbatim in the original language and translated into English by the local implementing partners. Content analysis method was used. The focus group interview data were coded by two members of the research team (AL & SFL) separately using a deductive coding process, with a focus on understanding the participants' knowledge, attitude, and help seeking intention and behavior for dementia. Codes were then collated into themes which were compared across the countries. The qualitative data complimented the findings of the quantitative data, and this allows the examination of the level of agreement and disagreement across countries and between data sources. Triangulation of the two sets of findings (qualitative and quantitative findings) was carried out to generate deeper understanding of specific aspect of dementia literacy.

## Results

### Description of the survey participants

A total of 476 participants completed the survey. Table 1 shows the demographic characteristics of the respondents. About half of the respondents were males (46.2%), aged 31 or below (51.9%), married (45.4%), employed (46.2%), and had university education or above (49.7%). Two-thirds of subjects (61.2%) were living in privately owned flats. About a quarter (25.1%) were living with seven or more people in the household. There was a significant difference in gender, age, marital status, educational level, employment status and

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accommodation among the three countries. The sample from Cambodia had fewer males, older citizens (aged 51 or above), more married persons, less educated, and more unemployed persons than the samples from the Philippines and Fiji. About one-fifth of all respondents had personal contact with a family member suffering from dementia. More respondents from Fiji (8.7%) had contact with someone with a mental illness than the other two countries (4.0% in Cambodia and 2.3% in Fiji,  $p = 0.023$ ).

[please insert Table 1 here]

## Survey results

### *Knowledge about dementia*

Table 2 shows the means and standard deviations of ADKS scores and its subscales among the three countries. The total ADKS scores ranged from 16.48 to 16.77 (SD: 2.28-3.22) in the three countries. Participants from Cambodia reported higher knowledge in dementia progression (mean (SD) = 2.64 (0.81)) but lower knowledge in risk factors (mean (SD) = 2.97 (1.21)) and caregiving (mean (SD) = 2.07 (0.88)) compared to those in the Philippines and Fiji. On the other hand, the mean score in symptoms knowledge in the Philippines (mean (SD) = 1.82 (0.96)) and the mean score in dementia knowledge about treatment and management in Fiji (mean (SD) = 2.21 (0.83)) was the lowest compared to the other two countries.

[please insert Table 2 here]

### *Attitudes about dementia*

The mean total score of DAS in Fiji (mean (SD) = 93.68 (15.84)) and Cambodia (mean (SD) = 93.25 (13.52)) were slightly higher than the Philippines (mean (SD) = 92.95 (14.44)) (Table 2). Similar pattern was observed in the subscale of DAS ‘social comfort’.

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***Sources of Help-Seeking for Dementia***

Majority of the respondents from Cambodia (88.7%) and Fiji (89.3%) identified health care professionals as a source of dementia help seeking (Table 2). More than half of the citizens in Cambodia (58.7%) and the Philippines (65.9%) and one-third of the citizens in Fiji (34.7%) seek help from family members, and another significant portion seek help from their friends (Philippines: 28.4%, Fiji: 15.3%). It was also worthy to note that 27.3% of the respondents in Fiji reported religious figures as a source of dementia help seeking and about one-tenth of the citizens (9.1%) in Cambodia and the Philippines had such practice.

Bivariate analyses showed that dementia knowledge was associated with attitudes towards dementia (Table 3). Correlations were found between the total score of DAS and knowledge about assessment/diagnosis ( $r = 0.251, p < 0.01$ ), life impact ( $r = 0.160, p < 0.01$ ), caregiving ( $r=0.118, p < 0.05$ ).

Multivariate linear regression models in Table 4 showed that controlling demographics, ADKS total score was significantly associated with DAS total score ( $B=1.156, SE=0.247, p < 0.001$ ) in the three countries. In Cambodia, knowledge about risk factors of dementia ( $B=2.550, SE=1.001, p=0.012$ ) was significantly associated with DAS total (positive attitudes towards dementia). But in the Philippines, education level ( $B=6.490, SE=1.833, p=0.001$ ), knowledge about assessment/diagnosis ( $B=3.536, SE=1.294, p=0.007$ ) and disease progression ( $B=2.595, SE=1.170, p=0.028$ ) were associated with DAS total, while in Fiji, knowledge about life impact ( $B=6.374, SE=1.614, p < 0.001$ ) was the only predictor of the positive attitudes towards dementia.

[please insert Table 3 and 4 here]

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**Focus groups interview results**

A total of 54 participants (39 females and 15 males) were invited to join six focus group interviews to express their views on dementia. Using a deductive approach, the qualitative results were organized into three main themes: 1) knowledge about dementia, 2) attitudes towards people with dementia, and 3) source of help seeking for dementia. Table 5 summarizes the thematic findings by country with supporting quotes.

[please insert Table 4 here]

***Knowledge about dementia***

The participants across the three countries described having limited knowledge about dementia. Some participants described dementia as a natural process in old age as the brains were degenerating as we aged. Some participants mixed up dementia with depression, assuming these are the same. In Cambodia, some participants believed that dementia was the negative consequence of ‘Karma’ (previous life), as one of the informants indicated:

*Dementia is caused from our Karma as well. Yes, our Karma created from the ‘previous life’. At this stage, the memory became lost.*

***Attitudes towards people with dementia***

In Cambodia, sympathetic but helpless attitudes towards dementia were noted. Across the three countries, some participants felt that they were socially uncomfortable when the persons with dementia were around them as they were scared about their aggressive behavior. Nonetheless, participants in the Philippines indicated their accepting attitude towards dementia and asserted that patience was the key to help those with dementia. Some participants from Fiji showed their

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love to the persons with dementia by holding hands and prayed together. As the informants said,

*I would treat a person with dementia like a friend and make him happy. I would be a good listener.*

*I would hold their hands and pray. I would invite them to join some groups that would make them happy.*

Dementia treatment and care seemed to be connected with religious activities in Fiji. Some participants would invite the persons with dementia to join their groups or gatherings with the aim of making the persons with dementia happy. Notwithstanding, a certain degree of stigma existed in the community; as a result, some people in Fiji tried to hide their family members with dementia from the others.

### ***Sources of Help for Dementia***

Participants from the three countries revealed that their common help seeking sources were family members, friends and health care professionals (e.g. psychiatrists, physicians and nurses). In Cambodia, non-government organizations were also identified as the major source of help for seeking help for dementia. Other sources included neighbors, village leaders, health care facilities (e.g. health centers, geriatric centers, hospitals), Red Cross, and government units (e.g. Ministry of Health). Participants in the Philippines asserted that the World Health Organization (WHO), local government and the Department of Health were the best service providers for dementia care. As the informants asserted:

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*Psychiatrist and psychologist. World Health Organization*

*(because these are the people who work on health). They are*

*the ones who really know the problems in the community.*

However, in Fiji people inclined to seek help from pastors when they had queries about dementia. Some participants believed that individuals with dementia could pray to their God for spiritual help. However, some participants complained about the overcharges of some religious representatives and ineffective therapies from these religious representatives.

A common consensus seemed to be reached in the three countries: participants were mostly concerned about the limited resources in mental health in their countries.

## **Discussion**

This study is the first to examine dementia literacy in three West Pacific countries (Cambodia, the Philippines and Fiji), providing additional information about dementia literacy in LMIC. As this was the first study using validated scales to measure dementia literacy among citizens in the LMICs, comparisons could only be made with the general population in developed countries. Not surprisingly, the overall level of dementia knowledge (ADKS total mean score) in these West Pacific countries were comparatively lower than those reported in developed countries such as American older adults in primary care clinics (ADKS total mean score = 23.6) and American community-dwelling adults (= 23.4) (Carpenter et al. 2009; Howell et al. 2016). Nonetheless, this was comparable to the undergraduate nursing students in India (= 16.8) and Year 1 nursing students in Malta (=18.4) (Poreddi et al., 2015; Scerri & Scerri, 2013). This finding implies that public education to improve dementia literacy is in great need in these participating countries in the West Pacific.

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The citizens in these three countries had similar level of positive attitude towards dementia, (the qualitative findings echoed this point and showed that citizens were patient, sympathetic and supportive to persons with dementia) but these were comparatively lower than those health-related trainees in developed countries (O'Connor & McFadden, 2010; Scerri & Scerri, 2013; George et al., 2013). The low mean score of DAS social comfort reflected that the citizens did not feel comfortable to interact with persons with dementia. The qualitative findings echoed the survey findings, as the informants asserted that they were scared of the aggressive behavior made by persons with dementia. Social comfort is a crucial determinant to dementia help seeking. Community-based dementia educational services should be set up so that the citizens could build up their social comfort when persons with dementia are around them.

As indicated in this study, substantial percentage of the citizens inclined to seek help from their family members or friends when they had queries about dementia. Qualitative findings of this study also echoed this point as the informants of the Philippines admitted that family members were the first source of help, and the government should be made themselves available to help the families. To advocate for a person-centred approach in dementia, we encourage help-seeking from different sources, including family and significant others (Tomczk et al., 2018). Family members should be trained for better understanding of the symptoms of dementia, and their roles in dementia care. The qualitative findings indicated the confusion among dementia, normal aging and depression. Wide public health initiatives or educational campaigns that highlight the distinction between dementia and normal aging, or between dementia and depression is recommended.



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Another major finding of the current study was about the importance of religious figures as the source of help in dementia in these countries. The findings of the current study supported the statement made by the previous studies: the religious figures could be the significant persons for offering psychological support and help to the laypersons (Giebel et al., 2017). Religious beliefs interact with wider social structure in these countries, affecting the citizens' perception of the uncertainty of resources in the community (McNamara & Henrich, 2018). For the situations where uncertainty arised, citizens in these LMIC countries inclined to relay the situations to punitive supernatural beliefs (McNamara & Henrich, 2018). The finding of the current study, which echoes the social decisions made by the citizens in these countres, highlights the importance of religious figures in dementia education. The qualitative data in dementia knowledge complimented the quantitative findings by providing interesting conceptions (or myths) about the possible causes of dementia. Participants in the focus group interviews related the cause of dementia to 'previous life' or punishment from God. Religious and cultural factors seemed to be strong in these countries, affecting the citizens' understanding of the actual causes of dementia and their motivation to seek help from western medicine. To address the issues in dementia literacy, religious and cultural factors should not be missed (Levin-Zamir et al., 2017). Places for religious gatherings seem to be appropriate venues for dementia education in these countries.

In this study, we showed the significant relationship between dementia knowledge and attitudes towards dementia, and the conceptual model of dementia literacy, proposed by Low and Asley (2009), was supported. We also noted different predictors of positive attitudes towards dementia were found in different countries. This implied that public education for cultivating

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positive attitudes towards dementia should be made in consideration of the country-specific needs.

There are some limitations to this study. First, although validated survey questionnaires and the WHO guidelines were used to guide the translation and back-translation of the measures, psychometric properties of the instruments were not formally tested in the study populations. Second, the recruitment strategy may have introduced selection bias because convenience sampling was used rather than random selection, which limits generalizability of the study results. Third, identifying sources of help seeking did not equate with actual help seeking behavior. Future research could capture the actual behaviour in help seeking in these countries. Fourth, the qualitative data may not completely cover all facets of the topics because only two focus group interviews were held in each country. Such design was made due to the limited resources in these countries, although the project team was aware of the importance of data saturation in qualitative study. Having additional focus groups may generate new insights on the topic with more diverse participants. Fifth, the interview transcripts in Fiji were translated into English. It is therefore possible that some of the meaning may have been lost when data were analyzed and interpreted. Lastly, the validated scales used in this study may not easily capture the cultural and religious reasoning about dementia among the West Pacific countries. Items related to the perceived causes of dementia, perceived risk factors and colloquial treatment or therapies should be included in the survey in future research. Qualitative research will also be helpful to identify the rationale behind for such perceptions. Despite of these limitations, the results provide unique insight into the current levels of dementia literacy in LMIC within the Western Pacific region, highlight important areas of educational needs to direct future educational campaigns and dementia policies.

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## Conclusions

This study reported the level of dementia literacy among citizens in the three LMICs in the Western Pacific region. In general, the Western Pacific citizens were sympathetic towards people with dementia. They mostly approached health care professionals and family members for seeking help in dementia, but religious figures stood out as important source in these countries. We recommend increasing resources in public education in dementia and provide training to cover different aspects of dementia according to the needs in different countries. The governments, policy makers, professionals and citizens of the participating countries should work together to advocate for the improvement of dementia literacy and refine dementia policy/services to meet local needs.

## Acknowledgements:

This project was funded and commissioned by World Health Organization. Special thanks go to the Ministry of Health of Cambodia, the Philippines and Fiji which provide resources and manpower to support the development of questionnaires, key areas of investigation in the study, study design and data collection. We sincerely thank the voluntary participants for their time on responding the survey or joining the focus group interviews and the university students and voluntary community health workers who supported data collection in these countries.

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**Table 1. Participants' demographic characteristics and contact experience with a person with dementia**

Demographic Characteristics		Survey participants				Focus Group interviews		
		Total (n=476)	Cambodia (n=150)	Philippines (n=176)	Fiji (n=150)	Cambodia (n=20)	Philippines (n=18)	Fiji (n=16)
<b>Gender</b>	Male (n, %)	220 (46.2)***	44 (29.3)	100 (57.5)	76 (51.0)	2 (10.0)	4 (22.2)	9 (56.3)
<b>Age</b>	<31	245 (51.9) ***	47 (31.3)	111 (63.1)	87 (59.6)	7 (35.0)	7 (38.9)	3 (18.8)
	31-50	161 (34.1)	68 (45.3)	48 (27.2)	45 (30.8)	6 (30.0)	3 (16.7)	11 (68.7)
	>51	66 (14.0)	35 (23.4)	17 (9.7)	14 (9.6)	7 (35.0)	8 (44.4)	2 (12.5)
<b>Marital Status</b>	Married (n, %)	216 (45.4) ***	112 (74.7)	50 (28.4)	54 (36.0)	13 (65.0)	8 (44.4)	10 (62.5)
	Others (n, %)	260 (54.6)	38(25.3)	126(71.6)	96(64.0)	7 (35.0)	10 (55.6)	6 (37.5)
<b>Education level</b>	<=Primary (n, %)	77(16.2) ***	62 (41.3)	8 (4.6%)	7 (4.7%)	10 (50.0)	1 (5.6)	0(0)
	Secondary (n, %)	162(34.1)	72 (48.0)	49 (28.0)	41 (27.3)	8 (40.0)	4 (22.2)	5 (31.3)
	>=University (n, %)	236(49.7)	16 (10.7)	118 (67.4)	102 (68.0)	2 (10.0)	13 (72.2)	11 (67.7)
<b>Employment Status</b>	Employed (n, %)	219(46.2) ***	57 (38.0)	64 (36.8)	98 (65.3)	11 (55.0)	14 (77.8)	14(87.6)
	Unemployed (n, %)	61(12.9)	34 (22.7)	12 (6.9)	15 (10.0)	9 (45.0)	4 (22.2)	1 (6.2)
	Others/retired/students (n, %)	194(40.9)	59 (39.3)	98 (56.3)	29 (24.7)	0 (0)	0 (0)	1 (6.2)
<b>Accommodation</b>	Privately Owned (n, %)	288 (61.2)**	97 (64.7)	103 (59.9)	88 (59.1)	14 (70.0)	14 (77.8)	44 (68.8)
	Rented Accommodation	141 (29.9)	45 (30.0)	52 (30.2)	44 (29.5)	6 (30.0)	3 (16.6)	5 (31.2)
	Government/public (n, %)	42 (8.9)	8 (5.3)	17 (9.9)	17 (11.4)	0 (0)	1 (5.6)	0 (0)
<b>No. of people in the household</b>	1-3 (n, %)	114(25.8)	41 (27.3)	41 (26.8)	32 (23.0)			
	4-6 (n, %)	217 (49.1)	68 (45.3)	75 (49.0)	74 (53.2)			
	7 or more (n, %)	111 (25.1)	41 (27.3)	37 (24.2)	33 (23.7)			
<b>Contact with a person with mental illness</b>	Family (n, %)	95 (20.0)	29 (19.3)	35 (19.9)	31 (20.7)	4 (20.0)	4 (22.2)	7 (43.8)
	Friend (n, %)	57 (12.0)	10 (6.7)	25 (14.2)	22 (14.7)	0 (0)	2 (11.1)	4 (25.0)
	Colleague (n, %)	23 (4.8)*	6 (4.0)	4 (2.3)	13 (8.7)	2 (10.0)	3 (16.7)	0 (0)
	Neighbor (n, %)	42 (8.8)	14 (9.3)	16 (9.1)	12 (8.1)	3 (15.0)	3 (16.7)	0 (0)

Note. \*\*\* p <0.001, \*\* p < 0.01, \* p<0.05; In marital status, 'others' stands for 'single/cohabited/widowed/divorced'

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**Table 2. Participants' dementia knowledge, attitude towards dementia and help seeking**

**behavior**

	Country		
	Cambodia	Philippines	Fiji
<b>Dementia Knowledge (mean, SD)</b>			
ADKS: total	16.77 (2.28)	16.68 (3.22)	16.48 (3.07)
ADKS: risk factors (6 items)	2.97 (1.21)	3.03 (1.29)	3.40 (1.24)
ADKS: Assessment and diagnosis (4 items)	2.61 (0.72)	2.68 (0.87)	2.70 (0.80)
ADKS: symptoms (4 items)	2.19 (0.92)	1.82 (0.96)	2.19 (0.93)
ADKS: disease progression (4 items)	2.64 (0.81)	2.38 (0.95)	1.87 (1.01)
ADKS: life impact (3 items)	1.81 (0.76)	1.97 (0.83)	2.01 (0.90)
ADKS: caregiving (5 items)	2.07 (0.88)	2.48 (1.04)	2.09 (0.84)
ADKS: treatment and management (4 items)	2.49 (0.83)	2.34 (0.90)	2.21 (0.83)
<b>Attitude towards dementia (mean, SD)</b>			
DAS: total	93.25 (13.52)	92.95 (14.44)	93.68 (15.84)
DAS: social comfort	46.61 (8.89)	44.75 (7.74)	45.00 (8.62)
DAS: knowledge	46.64 (6.40)	48.09 (7.69)	48.53 (8.47)
<b>Seeking help from* (n, %)</b>			
Health Care Professionals	133 (88.7)	87 (49.4)	134 (89.3)
Family	88 (58.7)	116 (65.9)	52 (34.7)
Friends	13 (8.7)	50 (28.4)	23 (15.3)
Religious Figures	14 (9.3)	16 (9.1)	41 (27.3)
Neighbors	34 (22.7)	2 (1.1)	0 (0)

Note. ADKS: Alzheimer's Disease Knowledge Scale; DAS: Dementia Attitude Scale

\*Respondents can choose more than one source as their preferred source of help seeking, therefore the sum of the percentage is greater than 100%

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**Table 3. Correlations between dementia knowledge and attitudes towards dementia**

	DAS comfort	DAS knowled ge	ADK S: risk factor s	ADKS: Assessment/ diagnosis	ADKS: symptoms	ADKS: disease progression	ADKS: life impact	ADKS: caregiving	ADKS: treatment management
DAS Total	.919**	.898**	0.082	.251**	-0.012	0.015	.160**	.118*	0.072
DAS comfort	1	.652**	.112*	.211**	-0.043	0.016	.128**	0.083	0.054
DAS knowledge		1	0.028	.235**	0.023	0.017	.175**	.107*	0.073
ADKS: risk factors			1	.201**	.173**	0.033	0.016	0.052	0.038
ADKS: Assessment/diagnosis				1	0.007	0.073	.178**	-0.005	.119**
ADKS: symptoms					1	-0.010	.156**	0.077	-0.053
ADKS: disease progression						1	-.097*	-0.069	.220**
ADKS: life impact							1	0.032	-0.076
ADKS: caregiving								1	0.006
ADKS: treatment/mx									1

Note. ADKS: Alzheimer's Disease Knowledge Scale; DAS: Dementia Attitude Scale



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**Table 4. Factors associated with positive attitudes towards persons with dementia**

	All countries						Cambodia						Philippines						Fiji					
	B	Std. Error	95% Confidence		p-value		B	Std. Error	95% Confidence		p-value	B	Std. Error	95% Confidence		p-value	B	Std. Error	95% Confidence		p-value			
			Lower Bound	Upper Bound					Lower Bound	Upper Bound				Lower Bound	Upper Bound				Lower Bound	Upper Bound				
Constant	63.163	5.839	10.818	51.687	74.639	<0.001	68.266	11.696	5.837	45.130	91.402	<0.001	51.396	9.560	5.376	32.502	70.290	<0.001	72.647	12.088	6.010	48.711	96.582	<0.001
Sex	2.786	1.384	2.013	0.066	5.507	0.045	3.177	2.626	1.210	-2.017	8.371	0.228	3.241	2.103	1.541	-0.915	7.396	0.125	-2.315	2.657	-0.871	-7.575	2.946	0.385
Age	0.011	0.008	1.269	-0.006	0.027	0.205	-0.045	0.086	-0.525	-0.216	0.125	0.600	-0.009	0.146	-0.064	-0.298	0.280	0.949	-0.001	0.010	-0.084	-0.020	0.019	0.933
<b>Education</b>	2.265	0.981	2.309	0.337	4.193	0.021	0.615	1.986	0.309	-3.314	4.543	0.757	6.490	1.833	3.541	2.868	10.113	<b>0.001</b>	1.441	2.391	0.603	-3.294	6.177	0.548
Marital Status	-1.907	1.480	-1.288	-4.816	1.002	0.198	4.347	2.833	1.535	-1.256	9.950	0.127	-5.450	3.674	-1.483	-12.710	1.811	0.140	-2.190	2.887	-0.759	-7.906	3.526	0.449
Employment	0.886	0.753	1.177	-0.594	2.365	0.240	0.381	1.328	0.287	-2.247	3.008	0.775	1.066	1.199	0.889	-1.303	3.434	0.375	0.218	1.648	0.132	-3.045	3.482	0.895
ADKS total	1.156	0.247	4.676	0.670	1.642	<0.001																		
<b>ADKS: risk factors</b>							2.550	1.001	2.548	0.570	4.530	<b>0.012</b>	-0.300	0.849	-0.353	-1.978	1.378	0.724	-0.629	1.286	-0.489	-3.175	1.918	0.626
<b>ADKS: assessment/diagnosis</b>							3.146	1.712	1.838	-0.240	6.532	0.068	3.536	1.294	2.732	0.978	6.093	<b>0.007</b>	2.561	1.794	1.427	-0.992	6.113	0.156
ADKS: symptoms							-0.712	1.276	-0.558	-3.235	1.812	0.578	0.159	1.100	0.144	-2.016	2.334	0.885	-1.649	1.708	-0.965	-5.032	1.734	0.336
<b>ADKS: disease progression</b>							-0.706	1.432	-0.493	-3.540	2.127	0.623	2.595	1.170	2.219	0.284	4.907	<b>0.028</b>	-1.203	1.391	-0.865	-3.958	1.551	0.389
<b>ADKS: life impact</b>							-2.048	1.556	-1.316	-5.126	1.031	0.190	1.184	1.298	0.912	-1.381	3.750	0.363	6.374	1.614	3.948	3.177	9.571	<b>&lt;0.001</b>
ADKS: caregiving							2.520	1.349	1.868	-0.149	5.188	0.064	0.381	1.043	0.365	-1.681	2.443	0.716	2.697	1.581	1.706	-0.434	5.828	0.091
ADKS: treatment/management							0.874	1.428	0.612	-1.950	3.698	0.541	0.442	1.225	0.361	-1.979	2.863	0.719	1.731	1.648	1.050	-1.533	4.994	0.296
Adj. R2	0.07						0.064						0.239						0.128					

Note. ADKS: Alzheimer's Disease Knowledge Scale; DAS: Dementia Attitude Scale; dx = diagnosis; mx = management

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This is the peer reviewed version of the following article which has been published in final form: Leung, AYM, Leung, SF, Ho, GWK, et al. Dementia literacy in Western Pacific countries: A mixed methods study. *Int J Geriatr Psychiatry*. 2019; 34: 1815– 1825. which has been published in final form: <https://doi.org/10.1002/gps.5197> This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions

Table 5. Thematic findings of focus group interviews by country with supporting quotes

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Themes	Cambodia	Philippines	Fiji
Dementia knowledge	<p><b>Limited knowledge and misconception about dementia:</b>  <i>Dementia happened because when people were young they thought too much.</i></p> <p><i>Dementia is found in [those aged] 70 years old. Their brain cannot work and always get lost memory.</i></p> <p><i>Dementia is caused from our Karma as well. Yes, our Karma created from the 'previous life'. At this stage, the memory became lost.</i></p>	<p><b>Limited knowledge and misconception about dementia (mixed up with depression):</b>  <i>I think I heard about it and it's something like ... when a person became depressed.</i></p> <p><i>The illness will just get worse because, with dementia, your brain cells get damaged through ageing so you become less sound.</i></p>	<p><b>Fair idea about causes and symptoms of dementia:</b>  <i>Dementia is a condition of memory loss observed in old age.</i></p>
Attitude towards dementia	<p><b>Sympathetic but helpless attitude towards dementia:</b>  <i>They are so miserable! For me, only pity them. What I have seen? It is hopeless for people with dementia.</i></p> <p><b>Scary attitude towards dementia:</b>  <i>I dared not visit [these people] because they lived alone. If there were any problems, they accused us. Visitors are afraid of them. I feel that they are scary, so scary!</i></p>	<p><b>Patient attitude towards dementia:</b>  <i>Patience is really needed even if sometimes what he says might be repetitive. Your patience really needs to be long enough.</i></p> <p><i>They need someone who are patient enough to remind them of the things they have forgot. If someone don't have patience and get angry with them, people with mental problems could be worsened.</i></p> <p><i>With dementia, only the memory is affected, so they still have their emotions.</i></p>	<p><b>Accepting / supportive attitude:</b>  <i>I would treat a person with dementia like a friend and make him happy. I would be a good listener.</i></p> <p><i>I would hold their hands and pray. I would invite them to join some groups that would make them happy.</i></p> <p><b>Scary attitude towards dementia:</b>  <i>People who are mentally ill will be aggressive. They also have substance abuse problems. Community is scared of these people [with mental illness].</i></p>

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			<p><b>Helpless attitude</b> <i>Sometimes the families just keep it quietly for themselves to manage on their own.</i></p>
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<p>Sources of dementia help seeking</p>	<p><b>NGO as the major source of help for dementia. Other sources include: family members, friends, neighbors, village leaders and professionals:</b> <i>I think that only NGO can help.</i></p> <p><i>When they are old like this, their illness gets worse. So only their family can bring them to clinics to check health status and follow up.</i></p> <p><i>If they are poor, the village or sangkat leader is the only one who can help them, bring them to the hospital to get treated.</i></p> <p><b>Inadequate support and resources for people with mental illness:</b> <i>I think that the most important problem is: we don't have many health centers to cure mental illness in the village or community. If we have such illness, we don't have hospitals to cure it. Thus, it becomes serious!</i></p> <p><i>Yes! Yes! Lacking human resources in mental health services/health centers is the key factor leading to the early onset of dementia.</i></p>	<p><b>Immediate family members are the key source of help. Others include WHO, government and Department of Health:</b> <i>I think his own family. It'll be his family because they are the ones who assist him with whatever his problem is.</i></p> <p><i>If a person is financially and mentally unstable, the first source of help is the family. [Services from] the government should be made readily available because the families can get tired from taking care of their [sick] family member ...so there is a need for the programs that train [or support] the families.</i></p> <p><i>Psychiatrist and psychologist. World Health Organization (because these are the people who work on health). They are the ones who really know the problems in the community.</i></p> <p><b>Inadequate support and resources for people with mental illness:</b> <i>The government has no initiative when it comes to mental health.</i></p>	<p><b>Family, friends and health professionals are the key source of help for dementia:</b> <i>We would mostly seek help from family members, friends and health care providers.</i></p> <p><i>A healer (hindu priest) who took advantage of the family by taking money to perform some sort of advice that did not work.</i></p> <p><b>Inadequate support and resource for people with mental illness:</b> <i>No support is given to people with mental disorders.</i></p> <p><i>Community is scared of these people. No support.</i></p>
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