Investigating dementia literacy among community-dwelling adults and older adults in Macau: A mixed methods study

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**Investigating dementia literacy among community-dwelling adults and
older adults in Macau: A mixed methods study**

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Abstract

Background: As population ageing and dementia incidence continue to increase worldwide, health systems are urged to empower the public to address factors related to dementia. This study aims to assess Macau citizens' knowledge of dementia, attitudes towards persons with dementia, and help-seeking behaviours and intention toward dementia.

Methods: This is a mixed-methods study with both quantitative (cross-sectional survey) and qualitative components (focus group interviews). The Alzheimer's Disease Knowledge Scale (ADKS) and Dementia Attitude Scale (DAS) were utilized in the quantitative data collection, whereas focus group interviews were employed to gather context-specific understanding of dementia in the local setting. Descriptive statistics and Chi-square tests were used to analyze quantitative data, while content analysis was used for qualitative data.

Results: The overall level of knowledge on dementia was low (ADKS mean total score = 17.38, SD = 3.31), with the least amount of knowledge in the caregiving domain. Meanwhile, attitudes toward persons with dementia was generally positive (mean [SD] = 89.07 [11.99]). Many of the focus group participants were also uncertain regarding the availability of dementia services in the region. The general public was interested to obtain dementia information through social media.

Conclusions: Efforts should be made to build up dementia literacy in Macau, especially in terms of caregiving. Information about dementia could be disseminated in social media and by healthcare professionals.

Keywords: *caregivers, Chinese, dementia, dementia literacy, service needs*

26 **Background**

27 Macau, one of the two Special Administrative Regions of China, is a small city with
28 700,000 citizens; but in 2012, it ranked second on the list of countries and regions with the
29 longest life expectancy in the world, which is 84.43 years [1]. The Macau government is
30 making efforts to promote the provision of care for elderly people with chronic illnesses, while
31 dementia is one of the key health concerns that the government has prioritized [1]. As rates of
32 cognitive decline continue to increase [2], investigating dementia literacy in the region will
33 help in efforts to develop appropriate services for persons with dementia (PWD), in the
34 formulation of community education programmes, and in the development of relevant public
35 health policies for the region.

36 In Macau, there are about 4,000 PWD [3]. Despite the high prevalence of dementia in
37 the community, the Chinese general public does not possess sufficient knowledge about the
38 condition [4]. In a survey with 3,007 community-dwelling older adults in China (covering 34
39 urban cities), the overall dementia literacy was 55% [5]; whereas another study among 354
40 elderly Chinese Americans revealed lower rates at 28.8% [6]. ‘Dementia literacy’ has been
41 defined as “*knowledge and beliefs regarding dementia that aid recognition, management or*
42 *prevention*” [7]. There is a general consensus that dementia literacy is about more than
43 ‘knowledge of dementia’; and should also include ‘beliefs regarding dementia’ – that is,
44 ‘attitudes towards persons with dementia’ and the ‘intention to seek help’. People with negative
45 attitudes would feel uncomfortable when PWD are around them, and do not feel obligated to
46 support these patients [8].

47 Cultivating dementia literacy in the community reduces stigmatization and encourages
48 community members to provide essential support to patients and relatives [9,10]. Evidence has
49 been shown that stigmatization about dementia existed in Chinese community and this delayed
50 access to essential health services [11]. Developing dementia health literacy in the community

is therefore essential, as doing so will support both patients and caregivers, and cultivate harmony in society. Therefore, this study aims to: 1) assess knowledge of the prevalence, symptoms, treatment options, and prognosis of dementia; 2) assess attitudes towards PWD; and 3) assess help-seeking behaviour and intention in dementia.

Methods

This is a mixed-methods study with a quantitative (a cross-sectional survey) and a qualitative component (focus group interviews). This design was employed to combine elements of the two approaches that will provide a deeper understanding of the concept under study [12]. Data collection was conducted in Macau from July 2017 to January 2018. There were three key domains of dementia literacy: knowledge of dementia, attitudes towards PWD, and help-seeking behaviour and intention.

Quantitative component: Cross-Sectional Survey

Survey measures

The survey written in Traditional Chinese includes three outcome measures: Alzheimer's Disease Knowledge Scale (ADKS), Dementia Attitudes Scale (DAS), and mode of delivering dementia information. ADKS is a 30-item scale with true/false questions that assess knowledge related to the assessment, diagnosis, caregiving, life impact, prevalence, prevention, risk factors, symptoms, treatment, and management of Alzheimer's disease [13]. The internal consistency (Cronbach's $\alpha = 0.71$) and its test-retest reliability (reliability coefficient = 0.81, $p < 0.001$) in the general population was good [13]. DAS is a 7-point Likert scale (strongly disagree = 1 and strongly agree = 7), with Cronbach's alphas ranging from 0.83 to 0.85 [14]. The total score of the DAS is the sum of all of its items: the higher the score, the more positive the attitudes towards PWD.

The participants were asked to indicate the existing channels (television, leaflets, WeChat, Facebook, etc.) and preferred channels for obtaining relevant information about dementia services. A list of services or support to PWD in the community was given. The respondents were also asked to rate their preference, ranging from “0” (least preferred) to “5” (most preferred). Demographic information about the participants was collected.

Sample for the Surveys

Using a stratified sampling method, we recruited 200 Macau citizens to join the survey. According to the population ratio in Macau [15], we approached 109 Macau citizens aged 15-44 (with 55 males and 54 females), 68 citizens aged 45-64 (34 males and 34 females), and 22 citizens aged 65 or above (11 males and 11 females) for the survey via non-governmental organizations (NGOs) and personal networks. The inclusion criteria were: aged 18 or above, cognitively intact (Short Portable Mental Status Questionnaire, SPMSQ >7), and able to read Chinese or communicate in Cantonese or Putonghua; The exclusion criteria were: being hospitalized and living in a residential care home.

Qualitative component: Focus group interviews

Three focus group interviews were conducted with two facilitators. A vignette showing the symptoms of dementia was developed by the project team in consideration with the Chinese cultural and contextual relevance in Macau [16]. A discussion was conducted based on the contents of the vignette as well as the informants’ experience. Guiding questions were used to stimulate the informants to discuss issues related to dementia. Audio-tape recording of the interviews was made, upon approval of the participants.

Sample for the Focus Group Interviews

A purposive sampling method was used, wherein 23 Macau citizens were recruited by NGOs or through personal networks. The inclusion and exclusion criteria were the same as those in the survey. People at different ages were invited, including older adults and caregivers.

Data analysis

Quantitative survey data were input and analyzed using IBM Statistical Package for the Social Sciences (SPSS) version 23. Multiple imputation was used to handle missing values. A descriptive analysis was conducted for the participant demographics, ADKS and DAS data, and items for measuring help-seeking behaviour and intention. Interviews were transcribed verbatim and content analysis was used. Three members of the project team coded the transcription independently and identified the themes. A comparison of the codings was made, and a consensus was reached after discussion.

Results

Profile of the participants

Table 1 shows the demographic characteristics of the participants in the survey. Half (53.5%) were females and only 23.0% of the respondents had previous contact with a person with dementia. Another 23 Macau adults were included in the three focus group interviews.

Table 1. Demographics of the participants in the survey and the focus group interviews

Demographic characteristics	Survey (n=200)		Focus group interviews (n=23)	
	Count	%	Count	%
Sex				
Male	93	46.5%	9	39%
Female	107	53.5%	14	61%
18-44	110	55.0%	8	35%
45-64	68	34.0%	9	39%

65+	22	11.0%	6	26%
Employment status				
Employed Full-time	109	55.6%	11	48%
Employed Part-time	13	6.6%	3	13%
Unemployed	14	7.1%	0	0%
Retired	44	22.4%	6	26%
Student	11	5.6%	2	9%
Housewife	5	2.6%	1	4%
Highest academic qualification				
No formal schooling	6	3.0%	0	0%
Primary or below	34	17.3%	5	22%
Secondary	87	44.2%	8	35%
University/College	64	32.5%	6	26%
Master or Above	6	3.0%	4	17%
Marital status				
Single	65	33.2%	7	30%
Married	111	56.6%	16	70%
Cohabited	2	1.0%	0	0%
Widowed	11	5.6%	0	0%
Divorced	7	3.6%	0	0%
Accommodation				
Privately owned house/flat	139	73.9%	19	83%
Rented accommodation	22	11.7%	4	17%
Public/government Housing	27	14.4%	0	0.0%
Number of persons in the household				
1	17	9.1%	2	9%
2	32	17.1%	1	4%
3	55	29.4%	9	39%
4	53	28.3%	6	26%

5	17	9.1%	1	4%
6 or more	13	7.0%	2	9%
missing			2	9%

Knowledge about dementia and its prevalence

The majority of the respondents (143/199, 71.9%) were able to give correct answers to more than 15 items in the ADKS (Table 2). The mean score of the ADKS was 17.38 (SD 3.31). The respondents had the least amount of knowledge about caregiving. In the focus group interviews, the informants expressed that dementia was quite common among older adults and they admitted that they did not talk about this illness in the region.

Table 2. Responses to the 30-item Alzheimer's Disease Knowledge Scale (ADKS)

	Min.	Max.	Mean	SD	>50% items were correct
ADKS total score	9.00	27.00	17.38	3.31	143(71.9%)
ADKS subscales:					
- Risk factors	0	6	3.19	1.22	80 (40.2%)
- Assessment and diagnosis	0	4	2.35	0.98	93 (46.7%)
- Symptoms	0	4	2.47	1.09	99 (49.7%)
- Disease progression	0	4	2.27	0.96	88 (44.2%)
- Life impact	0	3	2.15	0.83	154 (77.4%)
- Caregiving	0	5	2.05	1.05	59 (29.6%)
- Treatment and management	1	4	2.91	0.93	134 (67.3%)

Note. n=199

Knowledge about the symptoms of dementia

Half of the respondents (99/199, 49.7%) in the survey were able to give correct answers to more than half of the items relating to dementia symptoms (there were 4 items in this

category) (Table 2). In the focus group interviews, the informants were able to describe symptoms of dementia such as the inability to name relatives, the loss of self-care ability, and forgetting to turn off the stove after cooking (please refer to Table 3 for the direct quotations from the focus group interviews).

Table 3. Direct quotations from focus group interviews

Theme/concept	Direct quotations
Dementia is prevalent in Macau	<p><i>Not many, but still there are (people with dementia). I think that ... the proportion of older adults ... in the overall dementia population ... is around 30%.</i></p> <p><i>It [Dementia] is common among the elderly. A few said that they have relatives with dementia.</i></p>
Under-reporting of dementia cases in Macau	<p><i>I think now there are more (dementia cases). In the past, we did not talk about it or we did not know about it.... Some (people) can have (dementia) at a young age. In other words, it is not an illness only for people in their seventies, eighties....</i></p>
Knowledge about the symptoms of dementia	<p><i>The medicine has been taken, but he/she said that the medicine has not been taken ... the nurse in the hospital said that he/she has taken the medication.... For example, he/she forgot to turn off the fire after the water had boiled.... Or he/she mistook sugar for salt ... they can't take care of their own living ... they forgot how to come back home when they went out....</i></p> <p><i>Yes, he is so senile that he cannot remember anything ... he cannot recognize himself or his own children.</i></p> <p><i>For instance, he/she might mistake the refrigerator for the wardrobe and vice versa, and put the clothes into the refrigerator ... and put the food, vegetables, and fish into the wardrobe.</i></p>
Assessment and diagnosis is the first step in the whole process	<p><i>I suggest that he/she consult a doctor first. In fact, a dementia medical centre opened in Macau in September of last year. I think that he/she should be assessed by a doctor ... and assessments, such as a cognitive functioning assessment should be performed. If he/she is diagnosed with dementia, medications might be used ... some brain training can be received to help him/her.</i></p>
Strategies to support persons with dementia	<p><i>Family members can make a nameplate for him/her if they allow him/her to go out and return home... [Interviewer (simultaneously): Oh, Okay ... make a nameplate for him/her]. Mark down the telephone number, contact person, as well as his/her address...</i></p>

	<p><i>Talk about something that will interest him/her. Let him/her start a topic, then gradually talk to him/her. They (PWD) mostly will talk about their past and their childhood. We can guide them to talk about things in the present. That is ... starting from the things in the past that they can remember. When they start to talk about a topic, we talk to them gradually.... When we talk more, they start to remember. Recently I am ... When did you come and visit me? That is ... to start with their topics, they normally talk about their past...</i></p> <p><i>Some of the non-government funded or government-owned elderly homes provide some places for ... people with dementia. In Macau, some homes/hostels are specialized and accept people with dementia.</i></p>
Understanding of the prognosis of dementia	<p><i>It seems that dementia ... cannot be altered from bad to normal. ... Same for medication... It cannot reverse his/her illness...</i></p> <p><i>...[It is possible to] slow it down but it (dementia) cannot be cured. The doctor said that it cannot be cured. The doctor has made it clear that ... he/she cannot recover ... but ... for instance, if treatment is not received, he/she may completely forget you within a year. If treatment is received, it [the dementia] may slow down for three to four months. That is, comparatively, it will slow down a bit, but he/she cannot recover. (The doctor) has made it clear that yes, it can only be slowed down...</i></p> <p><i>I think maybe it is okay for a year, but when it reaches the third year ... and later ... I will think of their (PWD) friends in the community. How about their friends or their families? ... As their health continues to deteriorate, it will get harder and harder for their caregivers.</i></p> <p><i>At the late stage, the ability to swallow will be lost.... My friend's mother at her late stage ... refused to eat. I think it was because she had difficulty in swallowing...</i></p>
Uncertain about caregiving	<p><i>Not sure how to handle this ... not sure what should be done ... what is the next step? ... If the conditions become worse, what should be done? How do I know it is better now?... That is, we do not know ... that is, is it becoming good or becoming bad? ... Well, what could be done to make it better?</i></p>
Attitudes towards persons with dementia: respect PWD's and family members' decision	<p><i>If they [PWD] disagree, they will not go there [nursing homes]. We [caregivers] respect their [PWD] decisions.</i></p> <p><i>Nevertheless, we had a discussion among the siblings, and (we) gave up [applying for nursing homes]. (We) are not going to apply. Thus, it rested on my family members ... to take care of him [the parent with dementia]. We will also employ a maid to take care of him (24 hours a day). Therefore, I think, this time it is also the family members who will offer help to him.</i></p>

	<p><i>If the family members can take care of them (PWD), then of course it will be better. If you cannot take care of them and need to go to work, you can only place them there [in an elderly home]. No other solution.</i></p> <p><i>Caregivers should possess the attributes like: they should care about and love the PWD, they need to accompany and always talk to the PWD, and they should be patient with the PWD and respect them.</i></p>
Positive attitude: feeling guilty to locate PWD to nursing home	<p><i>No matter how, an elderly home ... she seems really ... Although we have chosen a better elderly home for her, she will still be ... in fact (we) think that her life has become more boring and that [she] has [had to deal with] some changes [Interviewer (simultaneously): Yes...] and her quality of life has been lowered.</i></p>
Negative attitudes towards PWD: Worry about the safety issues	<p><i>I live next to with him [PWD]. If he is cooking ... selfishly speaking ... it is really dangerous. I am really worried about it.</i></p> <p><i>The older people and the children are living together. When he [PWD] has an outbreak of symptoms, he can be ... very emotional sometimes.... This will scare the children.</i></p> <p><i>When he [person with dementia] is scolding someone, it is better not to stimulate him. People with dementia can lose control of their emotions [Interviewer (simultaneously): Yes...]. They can scold people, and sometimes even beat others. If you go further and trigger them ... Since you are not their relatives ... The most important point ... is that ... I will choose to stay away from them ... because ... (I) do not know how crazy they can get...</i></p>
Negative attitudes: whose responsibility?	<p><i>We think that the most difficult time was going with her frequently for follow-up consultations. And the other thing was 'who would go this time?' Maybe we have a comparatively large family. Among us ... who was the one who took the responsibility to take care of her? ... This caused ... some bigger conflicts within the family.</i></p>
Help seeking and intention: willing to find out	<p><i>Actually, we are not quite sure in Macau which department provides this service [dementia service]... but we will find out ... because Macau is a small place.... If it really happens, we will ask about ... which is the appropriate department? ... [and] how to provide point-to-point service?</i></p>
Channels for getting dementia information	<p><i>Television is the best (channel). And ... or on the bus, post more posters. These methods can reach the majority of people.</i></p> <p><i>For dementia education...we could target for caregivers, middle-aged people, and retirees. They are very close to persons with dementia.</i></p>
Help-seeking behaviour:	<p><i>Family members are important. If the family members really cannot not handle it ...when it becomes worse and more severe, you should consult</i></p>

Family member is the first one to approach	<i>a doctor. After that, you should consult a social worker. Ask the social worker what can be done. This should help.</i>
Challenges encountered in help-seeking	<i>What resources do we have? Usually, it is the family members ... who will help him/her. The hospital only provides medications to him/her... Every half year, he/she goes to the hospital for a follow-up consultation, and medications will be provided. Then, he/she (a social worker) will say: "Some centres provide this kind of (dementia) intervention. In Macau there are many cases of senile dementia, therefore, it is difficult to obtain the service. My ... social worker has given me a letter for my mother to make an appointment for receiving (dementia) interventions. We were in the queue and waited for more than 1.5 years; finally, we decided to give up.</i>
Help-seeking behaviour: suggestions of facilities, and the services they know	<p><i>I hope that there are rehabilitation centres to help those people (with dementia). The Peak [the public hospital in Macau] is only one for medical consultations. After the consultations, they need rehabilitation centres.</i></p> <p><i>It seems that there is a service called "Personal Emergency Link Service". Their staff will regularly [call] you.... For instance, you as an older adult, after installing this service, the staff member will regularly ring you and talk to you.</i></p>

139

140

141 *Knowledge about assessment and diagnosis*

142 Most of the informants indicated that 'assessment and diagnosis' is the first step to

143 caring for PWD. One informant indicated that Macau had just opened a Dementia Centre in

144 September 2016, and that its services were comprehensive. However, not all of the informants

145 were aware of this service. This finding was in line with the responses in the survey, in which

146 only half of the respondents (93/199, 46.7%) were able to give correct answers to the items

147 related to dementia assessment and diagnosis.

148

149 *Knowledge about treatment and management*

The majority of the respondents to the survey (134/199, 67.3%) were able to give correct answers to more than half of the items under ‘treatment and management’. In the focus group interviews, the informants cited various strategies to support PWD. For example, making a name tag for the PWD, on which the caregiver’s name, address, and contact details can be shown. Some informants suggested to use music therapy, cognitive training, playing mahjong (a tile-based game which was developed in China in the early 20th Century and remains a popular game in Chinese community) to help the patients. They believed that nursing homes were the last resort of support when dementia advanced.

Knowledge about the prognosis of dementia

Less than half of the Macau citizens (88/199, 44.2%) had a good knowledge of the prognosis of dementia. In the focus groups, some informants expressed that even if treatments were given, the cognition of PWD would continue to decline and the condition would be worse in 3 or 10 years. This might have an impact on caregivers, family members, and the community.

Knowledge about caring for people with dementia

In the survey, ‘knowledge of caregiving’ was ranked lowest among the seven kinds of knowledge about dementia. The mean score for caregiving was 2.05 (SD 1.05) out of 5, and only one-third of the respondents (59/199, 29.6%) correctly answered at least half of the items in this category. The majority of the respondents admitted that they were not very familiar with dementia (69%) and felt frustrated because they did not know how to help people with dementia (58.5%). Moreover, about two-fifth (44%) admitted that they could not imagine caring for someone with dementia. In the focus group interviews, informants also admitted that they did not know how to handle PWD and what to do in caregiving.

175

176 *Attitudes towards persons with dementia*

177 The DAS scores ranged from 52 to 121, with the mean total scores (mean [SD] = 89.07
 178 [11.99]) indicating positive attitudes toward PWD. The majority of the respondents in the
 179 survey were not afraid of PWD (60.5%) and felt that PWD could enjoy life (69.0%); while in
 180 the focus group interviews, some informants thought that most of the neighbours would be
 181 willing to direct the PWD to go home when the PWD got lost. One informant asserted that
 182 family members used different resources (mostly within the family) to support the PWD, as
 183 they knew that they would need to wait for a long time to obtain government-funded PWD
 184 services. The quantitative data confirmed this point. A high percentage of the respondents
 185 (75.5%) in the survey indicated that they could do a lot to improve the lives of PWD. A male
 186 informant indicated that he and his family members felt extremely guilty to their mother, even
 187 though she had been in a quality elderly home because she had been lonely and bored. By
 188 contrast, some respondents held negative attitudes towards PWD. About half of the respondents
 189 in the survey did not feel confident around PWD (47.0%). In the focus group interviews, some
 190 informants indicated that they were afraid of being affected by PWD who might forget to turn
 191 off the stove and then walk away from home after cooking. One reported that her parent with
 192 dementia occasionally lost his temper, which scared the children who were living with him.
 193 Another informant suggested that when the PWD was in a bad temper, family members should
 194 not stimulate him and should keep well away from him. This was in line with the finding from
 195 the survey that about one-third of the respondents would avoid an agitated PWD (36%).

196

197 *Help-seeking behaviour and intention*

198 Informants in the focus group interviews expressed that the information about dementia
 199 was insufficient in Macau. The most preferred modes of information delivery were television

(45.5%), hospital websites (42.5%), and newspapers (39.0%) (Table 4). Discrepancies were found between the preferred mode and the existing mode of information delivery in television (preferred vs existing mode: 45.5% vs 28.5%, $p < 0.001$) and in other channels. About 30% of the respondents preferred to receive information from Facebook and WeChat, but not much information was being disseminated via these two social network sites at present. The respondents considered their family members as the most important people in dementia care. When family members were not available to provide help, resources from the community, such as day care centres (183, 91.5%), skills training services for patients and caregivers (162, 81%), and caregiver support services (162, 81%), will be the useful services for patients and caregivers. Nonetheless, two informants recalled the challenges that they faced when attempting to access dementia services, as they did not know the required procedures.

Table 4. Comparison between the preferred and existing modes of delivering information about dementia services

	Preferred mode		Existing mode		p-value
	Frequency	Percent	Frequency	Percent	
Television	91	45.5	57	28.5	<0.001
Hospital websites	85	42.5	64	32.0	<0.001
Newspapers	78	39.0	67	33.5	<0.001
Educational leaflets	72	36.0	-	-	-
Government websites	71	35.5	37	18.5	<0.001
Facebook	57	28.5	-	-	-
WeChat	55	27.5	-	-	-
Radio	47	23.5	40	20.0	<0.001
Non-government websites	41	20.5	29	14.5	<0.001
Magazines	31	15.5	19	9.5	<0.001
Instagram	16	8.0	-	-	-
Blogs	12	6.0	-	-	-
Professionals	91	45.5	46	23.0	<0.001
Friends	60	30.0	54	27.0	<0.001
Relatives	42	21.0	31	15.5	<0.001

Discussion

This study is the first to investigate dementia literacy in Macau, one of the Special Administrative Regions of China. The cultural context in Macau is unique as it has been colonized by Portugal for more than 100 years, but the Chinese culture is well preserved and continue to be maintained in the community. Aside from the previous investigation of dementia literacy in 34 cities in China [5], this study contributed to our understanding of dementia literacy in this special region. These findings have been summarized in Figure 1.

[Please insert Figure 1 here]

Figure 1. Conceptual Framework of Dementia Literacy

With the practice of filial piety in Chinese families [17], Macau citizens were most willing to support their parents with dementia although their knowledge about dementia symptoms and caregiving skills was not high. The ADKS total score in Macau was much lower than the scores achieved by American students, older adults, senior centre staff, dementia caregivers, and dementia professionals [13]. There are many reasons for the low level of dementia knowledge in Macau. One possible reason, as shown in the focus group interviews, was that people in the region ‘do not talk about the illness’. This best represents the concept of harmony in Chinese culture [17], in which dementia is considered as a taboo and people try to hide this illness from others, or some people misunderstand dementia as a ‘normal age-related memory loss problems’ [8].

Many Macau citizens were not aware of the existence of dementia assessment services, although these services have been in place for several years. For instance, free-of-charge cognitive assessments have been offered in seven health centres in Macau since 2016 [19]. Notably, low levels of knowledge of treatment and care leads to delayed diagnosis and poor planning of treatment and care [18]. Therefore, the Macau government and service providers

are recommended to put resources into publicizing how to access cognitive health services. Upon receiving a diagnosis of dementia, cognitively impaired older adults will receive subsequent follow-ups in a dementia clinic in the only public hospital in the region [19]. Other than the government's initiatives, Kiang Wu Nursing College of Macau offers comprehensive assessments, diagnosis, treatment, and support services for caregivers in its memory clinic [20].

Macau citizens were generally kind to persons with dementia, and they were willing to talk, care for, and live with persons with dementia [21, 22]. Nonetheless, some respondents were not comfortable about dealing with persons with dementia, particularly those with agitated behaviour. Cultivating positive attitudes towards dementia should be encouraged so that community members will be willing to develop contacts with PWD [22].

Traditional mass media outlets (such as television and newspapers) were the most preferred modes of delivery. It is worth working with these media outlets to develop public educational programmes about dementia and to introduce the availability of dementia services in the region. A robust evaluation of these health education campaigns conducted via mass media should be carried out so that the impact of mass media campaigns on knowledge, attitudes, and behaviours can be assessed [23]. Another option for public education is social media (Facebook, WeChat, Instagram), as a substantial number of respondents would like to receive dementia information from these channels. Nonetheless, these channels have not been fully utilized to promote dementia literacy. Social media has been shown to be an effective channel for health education and for communication among health professionals [24]. For example, developing an app for assessing dementia symptoms in older citizens is a project that is worthy of support.

Conclusions

The findings show that although Macau citizens have positive attitudes toward PWD, there is inadequate knowledge in terms of caregiving. Additionally, there is inadequate information dissemination among the availability of dementia-related services in the region. This study fills a gap in knowledge about dementia literacy and provide a good foundation for subsequent studies on dementia. This also provide insights for practitioners to utilize in developing appropriate strategies in dementia education in Chinese community. In terms of policy development, the current study provides a clear picture of the level of awareness of dementia in the society and the barriers to accessing the existing dementia services, thus providing guidelines for programmes and interventions that can be developed to address the identified problems.

Limitations

This study has several limitations. First, the scale for measuring the intention to seek information was developed by the project team because we could not find a relevant validated scale. Second, the informants in the focus group interviews expressed their views based on their experiences. These views may not be representative of the views of all Macau citizens.

List of abbreviations

PWD: persons with dementia; ADKS: Alzheimer's Disease Knowledge Scale; DAS: Dementia Attitude Scale; NGOs: non-governmental organizations; SPMSQ: Short Portable Mental Status Questionnaire; SPSS: Statistical Package for the Social Sciences

Declarations

Ethics approval and consent to participate

Both the Hong Kong Polytechnic University Human Subjects Ethics Sub-committee (HSEARS20170511002) and the Kiang Wu Hospital's Ethical Committee (reference number: REC-2017.01) approved this study. The subjects were informed that they would not be put at a disadvantage or be at risk of being neglected for treatment or services by the NGOs due to their participation or non-participation in this study. All of the participants who enrolled in this study provided their written informed consent to take part in it.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to privacy and ethical restrictions but are available from the corresponding author on reasonable request.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Figures

Figure 1

Conceptual Framework of Dementia Literacy