


BMJ Open Knowledge, attitude and practice of community-dwelling adults regarding advance care planning in Malaysia: a cross-sectional study

Mun Kit Lim,^{1,2} Pauline Siew Mei Lai ,² Pei Shan Lim,² Pei Se Wong,³ Sajaratulnisah Othman ,² Fadzilah Hanum Mohd Mydin²

To cite: Lim MK, Lai PSM, Lim PS, *et al.* Knowledge, attitude and practice of community-dwelling adults regarding advance care planning in Malaysia: a cross-sectional study. *BMJ Open* 2022;**12**:e048314. doi:10.1136/bmjopen-2020-048314

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-048314>).

Received 22 December 2020
Accepted 26 January 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹School of Pharmacy, Monash University Malaysia, Bandar Sunway, Selangor, Malaysia

²Department of Primary Care Medicine, University of Malaya, Kuala Lumpur, Wilayah Persekutuan, Malaysia

³School of Pharmacy, International Medical University, Kuala Lumpur, Wilayah Persekutuan, Malaysia

Correspondence to

Dr Pauline Siew Mei Lai;
plai@ummc.edu.my

ABSTRACT

Objectives This study aimed to assess the knowledge, attitude and practice (KAP) among community-dwelling adults in Malaysia regarding advance care planning (ACP), and its associated factors.

Design This cross-sectional study was conducted from July–September 2018.

Setting This study was conducted at the University Malaya Medical Centre, Kuala Lumpur, Malaysia.

Participants We recruited community-dwelling adults (ambulatory care patients or their accompanying persons) who were ≥21 years old and able to understand English or Malay. A 1:10 systematic sampling procedure was used. Excluded were community-dwelling adults with intellectual disabilities or non-Malaysian accompanying persons. A trained researcher administered the validated English or Malay Advance Care Planning Questionnaire at baseline and 2 weeks later.

Primary and secondary outcome measures The primary outcome was the KAP regarding ACP. The secondary outcomes were factors associated with KAP.

Results A total of 385/393 community-dwelling adults agreed to participate (response rate 98%). Only 3.1% of the community-dwelling adults have heard about ACP and 85.7% of them felt that discussion on ACP was necessary after explanation of the term. The desire to maintain their decision-making ability when seriously ill (94.9%) and reducing family burden (91.6%) were the main motivating factors for ACP. In contrast, resorting to fate (86.5%) and perceived healthy condition (77.0%) were the main reasons against ACP. Overall, 84.4% would consider discussing ACP in the future. Community-dwelling adults who were employed were less likely to know about ACP (OR=0.167, 95% CI 0.050 to 0.559, p=0.004) whereas those with comorbidities were more likely to favour ACP (OR=2.460, 95% CI 1.161 to 5.213, p=0.019). No factor was found to be associated with the practice of ACP.

Conclusions Despite the lack of awareness regarding ACP, majority of community-dwelling adults in Malaysia had a positive attitude towards ACP and were willing to engage in a discussion regarding ACP after the term ‘ACP’ has been explained to them.

INTRODUCTION

Advance care planning (ACP) is defined as ‘a process that aids a person regardless of their

Strengths and limitations of this study

- To date, the knowledge, attitude and practice of community-dwelling adults in Malaysia regarding advance care planning (ACP) has not been assessed. Findings from this study can assist policy-makers to decide if Malaysians are ready for ACP to be legislated in Malaysia.
- The recruitment of the community-dwelling adults was limited to a single site and therefore, may not be representative of all Malaysians.
- Acquiescence bias which is one type of response bias cannot be ruled out as a result of researcher-assisted administration of questionnaires.
- However, the participants were recruited using a systematic random sampling method in this study to reduce sampling bias and the psychometric properties of the questionnaires used in this study have also been validated to reduce the risk of acquiescence bias.

age and health status to understand and share their personal values, life goals and preferences toward future medical care’.¹ The concept which originated from developed countries has been implemented in these high-income countries to support patients’ end-of-life care.^{2–8} ACP aims to improve the quality of end-of-life care by enabling effective communication to ensure that care is concordant with an individual’s wishes particularly in the event when he or she loses the capacity to decide.^{9,10} Well-implemented ACP policies may benefit patients (as they may experience a higher sense of autonomy and satisfaction with their care), their families (as they may experience less emotional stress, depression, burden and better quality of life) and the healthcare system (which may see a reduction in unnecessary hospitalisations and healthcare expenditures).^{8,11–13} Despite the known benefits of ACP, the uptake of ACP remains low due to failure to engage



patients when needed.^{2 14 15} The implementation of ACP may be challenging due to the multifaceted and complex decision-making process in end-of-life care, as a result of the conflicting needs and perception among patients, healthcare professionals and healthcare systems.^{3 16–18} Race, religion and cultural values have also been found to influence attitudes towards ACP, particularly among Asians.^{3 19–25}

The Asian population account for 62.9% of the world's population.²⁶ However, ACP in developing countries (of which Asia is no exception) is not well known. Less is known about the extent of their knowledge, attitude and practice (KAP) towards ACP, as end-of-life care in Asia is usually regarded as a culturally-sensitive topic.^{27–29} Discussion of death has been often a taboo as it is perceived to be ominous.^{21 30 31} The strong influence of the principles of beneficence and non-maleficence in Asian cultures tend to discourage talk about end-of-life decisions in order to avoid conflict and provide hope for the patients.³² The influence of religion may also vary between the different ethnic Asian groups, with more religious individuals prefer to leave the topic of death to fate as it is beyond their control.²¹ Asians have also reported to embrace collectivism in decision-making and are more comfortable making decisions with family due to their family-centric culture.^{28 29 33} This may include expectation of filial piety in their children, a highly regarded key virtue which may affect the decision on withdrawal of life-sustaining treatment for their terminally ill parents.^{34–36} Deferred autonomy is also reported to be the norm in Asia as patients are more likely to relegate their decision-making authority to physicians, who are regarded highly among Asians.²⁹ In contrast, Western cultures are largely influenced by the principle of respect for individual autonomy which favours open discussions on end-of-life care and ACP.³⁷ Thus, it is crucial to have a better understanding of the views of Asians in order to enable policy-makers to navigate through the culturally-sensitive issues for successful implementation of ACP in Asian countries.

To date, there is a paucity of studies in developing countries to explore the views and readiness of primary care patients for ACP. Existing KAP studies on patients in the primary care setting were limited to developed countries or countries with enacted legislation such as Canada³⁸ and China.³⁶ Studies on ACP have been performed primarily in older or seriously ill patients such as patients with cancer, heart failure or end stage renal disease.^{14 39–47} The focus of prior studies on moribund patients could be a reflection of the reluctance of most stakeholders to engage in ACP earlier and preferred to delay until the issues were more clinically relevant.^{14 48} However, patients at advanced or terminal stage may be pressured to make an ill-informed decision.⁴⁹ Thus, there is a rational proposition to shift the focus of investigation regarding ACP to the non-terminally ill ambulatory patients in the primary care setting as it is the first point of healthcare contact.^{48 49} Two prior studies on ACP in Malaysia that were conducted on older adults²¹

and patients undergoing haemodialysis⁵⁰ reported low awareness regarding ACP. To date, ACP is not legislated in Malaysia and the KAP of community-dwelling adults in Malaysia has not been assessed.⁵¹ Hence, the aim of this study was to assess the KAP of community-dwelling adults and to determine its associated factors.

METHODOLOGY

This cross-sectional study was conducted from July to September 2018 at the University Malaya Medical Center (UMMC) in Kuala Lumpur, Malaysia. UMMC is a tertiary referral centre with 1617 beds. ACP is not performed routinely by any units in UMMC as ACP is not legislated in Malaysia. ACP services are only provided on an ad-hoc basis. We recruited community-dwelling adults (ambulatory care patients or their accompanying persons) who attended the primary care clinic at our setting, who were ≥ 21 years old and able to understand English or Malay. Excluded were community-dwelling adults with intellectual disabilities or non-Malaysian accompanying persons. The required sample size was estimated with the most conservative consideration, that is, when the proportion of the community-dwelling adults with the knowledge on ACP, $p=50\%$ to obtain the largest sample size. Therefore, the sample size required with a confidence level of 95% and $\pm 5\%$ precision and 80% power was 385.⁵² The main outcome measured was the KAP of community-dwelling adults towards ACP. The secondary outcomes were its associating factors.

Instruments

The validated English⁵³ and the Malay Advance Care Planning Questionnaire (ACPQ)⁵⁴ were used to assess the KAP. The ACPQ consisted of four domains: participant demographics, knowledge, attitude and practice of ACP. Questions such as 'Do you know what is advance care planning?' in the knowledge domain, 'Do you feel that the discussion on advance care planning would be necessary?' in the attitude domain and 'Would you consider to discuss on advance care planning in the future?' in the practice of ACP domain were used to explore the patients' KAP on ACP, respectively. After completion of the knowledge domain, a standard definition of ACP¹ was provided to participants to maintain conformity. For the attitude domain, patients who were in favour of ACP were required to answer the items in the 'justification for ACP' domain; while those who were not in favour of ACP, were required to answer items in the 'justification for not having ACP' domain. For the practice domain, patients who had intentions to plan for ACP were required to answer all remaining items in the practice domain.

Procedure

Systematic random sampling was conducted to reduce sampling bias. On each day of data collection, the researcher obtained a random number between 1 and 9 using a random number generator from the Math

Goodies Official Random Number Generator.⁵⁵ Each patient was given a queue number on registration at the triage counter. The first patient was selected based on the random number generated on that day. A 1:10 systematic sampling procedure was used as approximately 300 patients attended the clinic each day, and one researcher could only recruit approximately 30 patients (or their accompanying person) per day. All eligible patients or their accompanying persons were approached and the purpose of the study was explained using the participant information sheet. For those who agreed to participate, written informed consent was obtained. Depending on the participant's language preference, either the validated English or Malay ACPQ was administered by a trained researcher via face-to-face interview. Research-assisted administration of questionnaires was required because the ACPQ contained some medical terms that may require explanations. The time taken to complete the ACPQ was approximately 15–20 min.

Data analysis

Data were analysed with IBM SPSS V.22 (IBM Corporation). Normality was assessed using the Kolmogorov-Smirnov test. Since normality could not be assumed, continuous variables were presented as median and IQR, while categorical variables were presented as frequencies and percentage. The response of 'do not know' is an important finding as participants were not forced to either agree or disagree with statements if they 'did not know'. Hence, do not know responses were reported descriptively. Preselection of factors for multiple logistic regression analysis was conducted using a bivariate logistic regression to assess the independent effects of relevant factors on the KAP after test of multicollinearity. Variables that reported a p value of <0.25 in the bivariate logistic regression was included in the multivariate logistic regression to isolate the effects of potential confounders.⁵⁶

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS

Demographics

A total of 385/393 participants agreed to participate (response rate 98%). The majority were women (215, 55.8%) and Malay (148, 38.4%), with a median age of 61 years (range 22–88 years) (table 1). The most common comorbidities were hypertension (117, 30.4%), diabetes (103, 26.8%) and chronic kidney disease (25, 6.5%). No reason was provided for non-participation, and the researcher respected their decision by not asking for a reason.

Table 1 Participants' demographic characteristics

Demographic characteristics	N (%) (n=385)
Median age (years) (range)	61(22–88)
Age<65	242 (62.9)
Age≥65	143 (37.1)
Sex	
Female	215 (55.8)
Male	170 (44.2)
Ethnicity	
Malay	148 (38.4)
Chinese	144 (37.4)
Indian	93 (24.2)
Marital status	
Married	309 (80.3)
Single/divorced/widowed	76 (19.7)
Level of education	
Secondary (completed 12 years of education)	224 (58.2)
Tertiary (completed at least 15 years of education)	126 (32.7)
Primary (completed 6 years of education)	35 (9.1)
Religion	
Islam	148 (38.4)
Buddhism	111 (28.8)
Hinduism	76 (19.7)
Christianity	50 (13.0)
Employment status	
Currently employed	166 (43.1)
Non-employed	219 (56.9)
Retired*	162 (74.0)
Unemployed*	57 (26.0)
Age	
Age≥65*	132 (60.3)
Age<65*	87 (39.7)
Personal income/month	
>RM1000 (US\$240)	268 (69.6)
≤RM1000 (US\$240)	117 (30.4)
Living companion	
Living with someone	349 (99.6)
Living alone	36 (9.4)
Self-rated health status	
Good	336 (87.3)
Poor	49 (12.7)
Presence of comorbidities	
Cardiovascular disease	131 (34.0)
Diabetes mellitus	103 (26.8)
No underlying comorbidities	53 (13.8)

Continued

Table 1 Continued

Demographic characteristics	N (%) (n=385)
Other diseases	52 (13.5)
Renal diseases	25 (6.5)
Pulmonary diseases	21 (5.4)

*Proportion of patients among the non-employed.

Knowledge

Only 12 participants (3.1%) have heard about the term ACP and 20 (5.2%) were familiar with the concept of ACP. The majority have not heard of terms related to ACP such as 'surrogate-decision maker' (361/385, 93.8%), 'end-of-life decision making' (346/385, 89.9%), 'living will' (220/385, 57.1%) and 'durable power of attorney' (290/385, 75.3%). Among those who have heard about the term ACP or terms related to ACP, participants reported that mass media (62/385, 16.1%) was their most common source of information, followed by friends (39/385, 10.2%), reading materials (32/385, 8.3%), relatives (26/385, 6.8%) and family doctors (12, 3.1%). Only 75 (19.5%) community-dwelling adults have thought of writing a living will and 23 (6%) community-dwelling adults had written a living will.

Attitude

A total of 330 (85.7%) community-dwelling adults felt that discussion on ACP was necessary and 331 (86.0%) agreed that ACP services should be provided in primary

care clinics, after the term ACP has been explained to them. Majority (278, 72.2%) of the community-dwelling adults were willing to express their wishes if they had dementia (308, 80.0%), cancer (305, 79.2%), heart attack and on a breathing machine (283, 73.5%), or were in a coma (267, 69.4%).

Of the 385 community-dwelling adults, 311 (80.8%) were in favour of ACP. Justifications for favouring ACP were: 'I am aware that I could possibly lose my decision-making power as a result of becoming seriously ill or injured' (301, 96.8%), 'I want to be able to make my own decisions' (295, 94.9%) and 'I hope to not burden my family with my medical treatment preferences' (285, 91.6%). For those who were not in favour of ACP, the justifications were: 'I will take it as it comes, I have no control over my death' (64, 86.5%), 'I am currently healthy and there is no need to consider such decisions' (55, 77.0%) and 'I felt that it was best to leave my future to fate or God' (41, 55.4%) (table 2).

Practice

Of 385 community-dwelling adults, a total of 325 (84.4%) were willing to discuss ACP in the future. More than 80% of community-dwelling adults agreed that the topics for discussion to include cardiopulmonary resuscitation decision, the use of artificial breathing machine, tube feeding, place of death, haemodialysis, place of care and chemotherapy. In the event that they were unable to communicate their choices, majority of the community-dwelling adults chose their spouse (124, 38.2%) or family

Table 2 Justifications for and against advance care planning

Justifications	Strongly agree or agree N (%)	Do not know N (%)	Strongly disagree or disagree N (%)
Justification for having advance care planning (n=311)			
I am aware that I could possibly lose my decision-making power as a result of becoming seriously ill or injured	301 (96.8)	6 (1.9)	4 (1.3)
I want to be able to make my own decision	295 (94.9)	5 (1.6)	11 (3.5)
I hope to not burden my family with my medical treatment preferences	285 (91.6)	1 (0.3)	25 (8)
There may be differences in opinions between my family members	278 (89.4)	6 (1.9)	27 (8.7)
Justification for not having advance care planning (n=74)			
I will take it as it comes, as I have no control over my death	64 (86.5)	2 (2.7)	8 (10.8)
I am currently healthy and there is no need to consider such decisions	57 (77.0)	4 (5.4)	13 (17.6)
I felt that it was best to leave my future to fate or God	41 (55.4)	7 (9.5)	26 (35.1)
I cannot imagine myself in such a situation	38 (51.3)	9 (12.2)	27 (36.5)
I do not want to think that I will eventually die or lose my memory	35 (47.3)	10 (13.5)	29 (39.2)
I believed that planning of my death would mean that there is no hope for me	17 (23.0)	10 (13.5)	47 (63.5)
I believed that the discussion on the topic of death was seen as unlucky and I tried to avoid discussing about it	11 (14.9)	10 (13.5)	53 (71.6)

Table 3 Multiple logistic regression of factors influencing the knowledge, attitude and practice of community-dwelling adults towards advance care planning

Variables	B	OR (95% CI)	P value
Knowledge			
Hinduism	-0.255	0.585 (0.173 to 1.974)	0.712
Female	0.646	1.907 (0.681 to 5.345)	0.219
Buddhism	-0.914	0.401 (0.108 to 1.483)	0.171
Age \geq 65	-0.875	0.417 (0.130 to 1.340)	0.142
Tertiary level of education	0.977	2.686 (0.949 to 7.434)	0.063
Employed	-1.787	0.167 (0.050 to 0.559)	0.004*
Attitude			
Female	-0.127	0.880 (0.477 to 1.625)	0.684
Christianity	0.415	1.514 (0.500 to 4.585)	0.463
Monthly income \leq RM1000 (US\$240)	-0.461	0.631 (0.332 to 1.198)	0.159
Buddhism	-0.469	0.625 (0.334 to 1.172)	0.143
No formal and primary education	-0.679	0.507 (0.207 to 1.243)	0.138
Has comorbidities	0.900	2.460 (1.161 to 5.213)	0.019*
Practice			
Buddhism	-0.179	0.836 (0.450 to 1.551)	0.570
Tertiary level of education	0.490	1.632 (0.837 to 3.181)	0.150
Hinduism	0.684	1.983 (0.819 to 4.800)	0.129
Monthly income \leq RM1000 (US\$240)	-0.484	0.616 (0.340 to 1.115)	0.109

members (122, 37.5%) to convey their wishes on their behalf while the rest of them prefer healthcare providers (77, 23.7%) or close friends (2, 0.6%) as their surrogate-decision-makers. In terms of recording their ACP, 277 (84.2%) of the community-dwelling adults preferred a verbal directive to family member or acquaintance. In addition, 221 (67.2%) were also open to the idea of a written documentation and to give the copy to their healthcare provider and family. However, audio or video tape recording was the least preferred choice with only 74 (22.5%) of the community-dwelling adults agreed to this method of recording.

Factors associated with KAP of ACP

Community-dwelling adults who were currently employed were less likely to know about ACP (OR=0.167, 95% CI 0.050 to 0.559) (table 3). This model explained 5% of the variance ($F(6, 378)=3.307$, $p<0.05$). Those with comorbidities were more likely to favour ACP (OR=2.460, 95% CI 1.161 to 5.213). This model explained 3.9% of the variance ($F(6, 378)=2.568$, $p<0.05$). However, no factor was found to be associated with the practice of ACP ($F(4, 380)=2.568$, $p=0.051$).

DISCUSSION

Awareness of ACP was low (5.2%) among community-dwelling adults in Malaysia. Despite the low awareness, community-dwelling adults in Malaysia (85.7%) had a positive attitude towards ACP after the term ACP was

explained to them. In addition, 84.4% of the community-dwelling adults felt that ACP was necessary and would consider having a discussion on ACP.

Knowledge

Overall, the awareness of ACP was low among community-dwelling adults in Malaysia, where the majority have not heard about the term ACP. Interestingly, there were slightly more community-dwelling adults who were familiar with the concept rather than the term ACP, possibly due to the lack of publicity regarding the term ACP. When compared with other countries in Asia, older adults living in nursing homes in Hong Kong had similar awareness regarding ACP (4.0%).⁵⁷ However, community-dwelling adults in Singapore were more familiar with ACP (14.4%) when compared with Malaysian community-dwelling adults.⁵⁸ This may be due to lack of dedicated legislation or low public awareness of ACP in Malaysia and Hong Kong.⁵⁹ Programmes to educate the public regarding ACP are mainly conducted by non-governmental organisations such as Hospis Malaysia (a charitable palliative care service provider),⁶⁰ or ACP advisory service providers⁶¹ in an isolated manner. In contrast, national guidelines for palliative care⁶² and the Advance Medical Directive Act were enacted in Singapore in 2014 and 1996, respectively, which recommended that all terminally ill patients should have an advance care plan. This may have led to public discussions on ACP among the community dwellers in Singapore, thus increasing their awareness regarding ACP.

Attitude

Despite having a low awareness regarding ACP, community-dwelling adults in Malaysia had a positive attitude towards ACP after the term ACP has been explained to them. This result was similar to studies conducted in Hong Kong²⁵ and Singapore⁵⁸ where community-dwelling adults were more receptive to ACP when introduced to its definition and concept, indicating that knowledge and awareness could be a prerequisite to achieve a positive change in attitudes and belief towards ACP.^{63 64} Hence, awareness campaigns to help community-dwelling adults learn about ACP should be initiated using mass media, as mass media was the preferred source of information among Malaysians. The community-dwelling adults in our study also believed it was necessary for ACP to be provided in primary care clinics, which was similar to a study in Singapore which reported that 61% of the community dwellers would discuss ACP with their primary care physician.² This suggests that community-dwelling adults were comfortable with discussion on end-of-life care in the primary care setting.

Reducing family burden and the desire to maintain their decision-making ability when seriously ill were the main motivating factors for those who were in favour of ACP in our study, as preference for healthcare autonomy may contribute positively to the attitude of planning ahead.³⁶ The benefits of ACP in reducing the financial and emotional burden on the patients' family could also persuade some to adopt positive attitudes towards ACP.^{2 14} On the other hand, 'I am currently healthy' and 'I will take it as it comes as I have no control over my death' were the main reasons given by those who were not in favour of ACP. This finding was corroborated by several studies in which ACP was deemed inappropriate and unnecessary for healthy individuals.⁶⁵⁻⁶⁷ A qualitative Malaysian study conducted in 2007 also showed similar findings whereby those who were unwilling to have ACP, wanted to leave these matters to fate or God.²¹

Practice

Malaysian community-dwelling adults were as willing as Singaporean community dwellers (81.8%) to begin ACP discussion with their primary care physicians.² In comparison to studies conducted in western countries, our findings were significantly lower compared with studies conducted in Ireland⁶⁸ and in Australia.⁶⁹ Asians may be less willing than non-Asians to discuss end-of-life-care for several reasons. Talking about ACP is a societal taboo among Asians⁷⁰ as discussing about death or dying may bring bad luck and hence, this topic should be avoided.⁷¹ Moreover, making end-of-life decisions is thought to hasten death.⁷² With the lack of discussions about death and end-of-life care, it is not surprising to see the lack of communications on ACP among Asians compared with non-Asians.⁷³ From our results, verbal directive to family members was the preferred method in conveying their wishes in advance, and family members were the ideal surrogate decision-makers rather than healthcare

professionals. This may be due to the fear of blindly entering a legally binding advance directive. Our findings were consistent with other studies from Malaysia,²¹ Singapore,⁵⁸ Hong Kong,⁵⁷ Japan, Korea and China.⁷⁴ Previous study has also described Asians favouring family-centric decision-making in which most of them chose their family to make medical decisions for them when they become incapacitated, even if they have migrated to non-Asian countries.⁷⁵ This is probably due to strong trust and bonding between family members. Reciprocally, Asians were also more likely to forgo treatment of themselves rather than their family members, when they are in a terminal stage because it is unacceptable to be accused of unfilial for not treating their elderly parents.³⁶

Factors associated with KAP regarding ACP

Non-employed community-dwelling adults were almost six times more likely to know about ACP than employed community-dwelling adults. This may be because an employed person may have lesser time to learn about ACP due to their job commitments when compared with unemployed persons. Additionally, an employed person may perceive ACP as less relevant due to their priority on their career.^{5 14 58} In contrast, retired and older unemployed adults may have a higher appreciation of end-of-life care-related matters leading to them spending more time to research about ACP.⁵⁸

Community-dwelling adults with more comorbidities were almost 2.5 times more likely to favour ACP as compared with those who were healthy, which was similar to previous studies.^{58 63} Most community-dwelling adults believed that discussion about ACP was unwarranted when they are healthy as it may exert unnecessary burden on the family.^{14 64} Some community-dwelling adults also felt that it was irrelevant and irrational to raise discussion related to end-of-life care during normal consultation on minor ailments with their physicians.⁶⁴ Hence, diagnosis of chronic conditions which may lower their perceived level of healthiness, possibly eliminating the barrier of perceived irrelevance of ACP.^{58 64} This is congruent with previous studies describing that discussions on ACP or end-of-life care often occur when an individual is in the advanced stages of a disease. Although 30.4% of the participants had a monthly income <US\$240, the low level of income did not influence their attitude towards ACP. Our finding was different from the findings of previous studies⁷⁶⁻⁷⁸ which reported better engagement towards ACP among community-dwelling adults with higher income. The difference in observation may be due to individual incomes (asked in our study) versus household incomes in other studies.⁷⁶⁻⁷⁸

No factor was found to affect the practice of community-dwelling adults in Malaysia on ACP. A possible explanation could be due to limited access and exposure to ACP and its concept in Malaysia. ACP is mainly promoted by non-governmental organisations promoting palliative care in the country without the support of legislative instruments and an established ACP framework or

system.^{60 79} The lack of guideline, protocol and system may result in patients' hesitation to commit to ACP until better clarity about its undertaking.^{14 64} Proper protocol with regulatory guidelines to promote protection of patients' interest, and clarity on the roles of various professionals and organisations pertaining ACP to ensure smooth conduct of ACP may help to remove the patients' doubts and thus, persuade them to initiate discussions on ACP.¹⁴

While prior studies have described the influence of religion on preference for ACP, we were not able to see any association in our study.^{18 21 28} Literature suggests that individuals with strong religious belief would have a negative attitude towards planning for end-of-life related matters due to their desire to leave these matters to fate.²¹ However, most of the community-dwelling adults in this study were receptive to the concept of ACP. This may be due to the western influences, and the Malaysian culture of accommodation and openness to new ideas.^{31 36 80 81}

One of the limitations of our study was the recruitment of community-dwelling adults from a single site which may affect the generalisability of this study. Recruitment from multiple sites should be considered in future studies. Second, acquiescence bias as a result of interviewer-assisted questionnaires cannot be ruled out. Third, the knowledge regarding ACP among the community-dwelling adults was self-reported by answering one question. The questionnaire used was designed as a preliminary assessment among populations which has low awareness regarding ACP because assessment of knowledge with a test would not be possible due to the low awareness. Despite the limitations, baseline findings from this study can assist policy-makers to decide if Malaysians are ready for ACP to be legislated in Malaysia. Moreover, the participants in this study were recruited using systematic random sampling method to reduce sampling bias. Another strength of this study was the use of a validated questionnaire to assess the community-dwelling adults' KAP towards ACP to minimise the risk of acquiescence bias.

CONCLUSIONS

Despite the lack of awareness regarding ACP, majority of community-dwelling adults in Malaysia had a positive attitude towards ACP and were willing to engage in a discussion regarding ACP after the term ACP has been explained to them. Community-dwelling adults who were employed were less likely to know about ACP whereas community-dwelling adults with comorbidities had a more favourable attitude towards ACP. No factor was found to be associated with the practice of ACP. Findings from this study can be used to inform the writing of guidelines, and legislative frameworks regarding ACP. Efforts to raise awareness regarding ACP in Malaysia can be directed to the community-dwelling adults with comorbidities using mass media.

Acknowledgements We would like to thank the staffs of primary care clinic in University Malaya Medical Centre for their assistance in data collection.

Contributors MKL, PSML, PSW, SO and FHMM conceived the study, participated in the design and reviewed the translated versions of the questionnaire. PSL and MKL were involved in data acquisition. MKL and PSML performed the analysis and interpretation of data. PSL and MKL drafted the manuscript. All authors read and approved the final manuscript. MKL and PSML had access to the data and accepts full responsibility for the conduct of the study.

Funding This work was supported by University Malaya Research Grant grant number RP048D-17HTM.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the name of the ethics committee: University Malaya Medical Centre Medical Ethics Committee Reference no. MEC 2018524-6316. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Pauline Siew Mei Lai <http://orcid.org/0000-0002-9940-9644>
Sajaratulnisah Othman <http://orcid.org/0000-0001-5786-1299>

REFERENCES

- 1 Sudore RL, Lum HD, You JJ, *et al*. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017;53:821–32.
- 2 Tay M, Chia SE, Sng J. Knowledge, attitudes and practices of the advance medical directive in a residential estate in Singapore. *Ann Acad Med Singap* 2010;39:424–8.
- 3 Johnson S, Butow P, Kerridge I, *et al*. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology* 2016;25:362–86.
- 4 Nishiguchi S, Sugaya N, Sakamaki K, *et al*. End-Of-Life care bonus promoting end-of-life care in nursing homes: an 11-year retrospective longitudinal prefecture-wide study in Japan. *Biosci Trends* 2017;11:54–61.
- 5 Schickedanz AD, Schillinger D, Landefeld CS, *et al*. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* 2009;57:31–9.
- 6 Simon JE, Ghosh S, Heyland D, *et al*. Evidence of increasing public participation in advance care planning: a comparison of polls in Alberta between 2007 and 2013. *BMJ Support Palliat Care* 2019;9:189–96.
- 7 Thomas R, Wilson DM, Justice C, *et al*. A literature review of preferences for end-of-life care in developed countries by individuals with different cultural affiliations and ethnicity. *J Hosp Palliat Nurs* 2008;10:142–61.
- 8 McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? A scoping review. *J Am Geriatr Soc* 2021;69:234–44.
- 9 Degenholtz HB, Rhee Y, Arnold RM. Brief communication: the relationship between having a living will and dying in place. *Ann Intern Med* 2004;141:113–7.
- 10 Pérez MdelV, Macchi MJ, Agranatti AF. Advance directives in the context of end-of-life palliative care. *Curr Opin Support Palliat Care* 2013;7:406–10.
- 11 Bakitas M, Lyons KD, Hegel MT, *et al*. Effects of a palliative care intervention on clinical outcomes in patients with advanced

- cancer: the project enable II randomized controlled trial. *JAMA* 2009;302:741–9.
- 12 Tierney WM, Dexter PR, Gramelspacher GP, *et al.* The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16:32–40.
 - 13 Detering KM, Hancock AD, Reade MC, *et al.* The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
 - 14 Simon J, Porterfield P, Bouchal SR, *et al.* 'Not yet' and 'Just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families. *BMJ Support Palliat Care* 2015;5:54–62.
 - 15 Heyland DK, Barwich D, Pichora D, *et al.* Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013;173:778–87.
 - 16 Boyd K, Mason B, Kendall M, *et al.* Advance care planning for cancer patients in primary care: a feasibility study. *Br J Gen Pract* 2010;60:e449–58.
 - 17 Emanuel LL, von Gunten CF, Ferris FD. Advance care planning. *Arch Fam Med* 2000;9:1181–7.
 - 18 Lovell A, Yates P. Advance care planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliat Med* 2014;28:1026–35.
 - 19 Chan HYL, Pang SMC. Readiness of Chinese frail old age home residents towards end-of-life care decision making. *J Clin Nurs* 2011;20:1454–61.
 - 20 Deshpande O, Reid MC, Rao AS. Attitudes of Asian-Indian Hindus toward end-of-life care. *J Am Geriatr Soc* 2005;53:131–5.
 - 21 Htut Y, Shahrul K, Poi PJH. The views of older Malaysians on advanced directive and advanced care planning: a qualitative study. *Asia Pac J Public Health* 2007;19:58–66.
 - 22 Low JA, Ng WC, Yap KB, *et al.* End-of-life issues—preferences and choices of a group of elderly Chinese subjects attending a day care centre in Singapore. *Ann Acad Med Singap* 2000;29:50–6.
 - 23 Radhakrishnan K, Saxena S, Jilapalli R, *et al.* Barriers to and facilitators of South Asian Indian-Americans' engagement in advanced care planning behaviors. *J Nurs Scholarsh* 2017;49:294–302.
 - 24 Sarhill N, LeGrand S, Islambouli R, *et al.* The terminally ill Muslim: death and dying from the Muslim perspective. *Am J Hosp Palliat Care* 2001;18:251–5.
 - 25 Ting FH, Mok E. Advance directives and life-sustaining treatment: attitudes of Hong Kong Chinese elders with chronic disease. *Hong Kong Med J* 2011;17:105–11.
 - 26 Worldometers.info. Worldometer Dover: Dadax, 2020. Available: <https://www.worldometers.info/world-population/asia-population/> [Accessed 15 Mar 2020].
 - 27 Berkman C. Advance care planning in Asian populations: knowledge, attitudes and behaviours. *International Association of Gerontology and Geriatrics World Congree*; July 2017, San Francisco, 2017.
 - 28 Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:634–41.
 - 29 Cheng S-Y, Lin C-P, Chan HY-L, *et al.* Advance care planning in Asian culture. *Jpn J Clin Oncol* 2020;50:976–89.
 - 30 Jahn Kassim PN, Alias F, Religious AF. Religious, ethical and legal considerations in end-of-life issues: fundamental requisites for medical decision making. *J Relig Health* 2016;55:119–34.
 - 31 Braun KL, Nichols R. Death and dying in four Asian American cultures: a descriptive study. *Death Stud* 1997;21:327–59.
 - 32 Searight HR, Gafford J. Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician* 2005;71:515–22.
 - 33 Rao AS, Desphande OM, Jamoona C, *et al.* Elderly Indo-Caribbean Hindus and end-of-life care: a community-based exploratory study. *J Am Geriatr Soc* 2008;56:1129–33.
 - 34 Su CT, McMahan RD, Williams BA, *et al.* Family matters: effects of birth order, culture, and family dynamics on surrogate decision-making. *J Am Geriatr Soc* 2014;62:175–82.
 - 35 Tang ST, Liu T-W, Lai M-S, *et al.* Concordance of preferences for end-of-life care between terminally ill cancer patients and their family caregivers in Taiwan. *J Pain Symptom Manage* 2005;30:510–8.
 - 36 Kang L, Liu X-H, Zhang J, *et al.* Attitudes toward advance directives among patients and their family members in China. *J Am Med Dir Assoc* 2017;18:808.e7–808.e11.
 - 37 Perkins HS, Geppert CMA, Gonzales A, *et al.* Cross-Cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med* 2002;17:48–57.
 - 38 O'Sullivan R, Mailo K, Angeles R, *et al.* Advance directives: survey of primary care patients. *Can Fam Physician* 2015;61:353–6.
 - 39 Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clin J Am Soc Nephrol* 2006;1:1023–8.
 - 40 Ganti AK, Lee SJ, Vose JM, *et al.* Outcomes after hematopoietic stem-cell transplantation for hematologic malignancies in patients with or without advance care planning. *J Clin Oncol* 2007;25:5643–8.
 - 41 Joffe S, Mello MM, Cook EF, *et al.* Advance care planning in patients undergoing hematopoietic cell transplantation. *Biol Blood Marrow Transplant* 2007;13:65–73.
 - 42 Michael N, O'Callaghan C, Clayton J, *et al.* Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice. *Support Care Cancer* 2013;21:2195–205.
 - 43 Robinson L, Dickinson C, Rousseau N, *et al.* A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing* 2012;41:263–9.
 - 44 Lewin WH, Cheung W, Horvath AN, *et al.* Supportive cardiology: moving palliative care upstream for patients living with advanced heart failure. *J Palliat Med* 2017;20:1112–9.
 - 45 Aslakson RA, Isenberg SR, Crossnohere NL, *et al.* Utilising advance care planning videos to empower perioperative cancer patients and families: a study protocol of a randomised controlled trial. *BMJ Open* 2017;7:e016257.
 - 46 Metzger M, Song M-K, Devane-Johnson S. LVAD patients' and surrogates' perspectives on SPIRIT-HF: An advance care planning discussion. *Heart Lung* 2016;45:305–10.
 - 47 Gludemans JJ, Moll van Charante EP, Willems DL. Advance care planning in primary care, only for severely ill patients? A structured review. *Fam Pract* 2015;32:16–26.
 - 48 Lamont EB, Siegler M. Paradoxes in cancer patients' advance care planning. *J Palliat Med* 2000;3:27–35.
 - 49 Otte IC, Jung C, Elger BS, *et al.* Advance directives and the impact of timing. A qualitative study with Swiss general practitioners. *Swiss Med Wkly* 2014;144:w14035.
 - 50 Hing Wong A, Chin LE, Ping TL, *et al.* Clinical impact of education provision on determining advance care planning decisions among end stage renal disease patients receiving regular hemodialysis in University Malaya medical centre. *Indian J Palliat Care* 2016;22:437–45.
 - 51 Kassim PNJ, Alias F. End-Of-Life decisions in Malaysia: Adequacies of ethical codes and developing legal standards. *J Law Med* 2015;22:934–50.
 - 52 Pourhoseingholi MA, Vahedi M, Rahimzadeh M. Sample size calculation in medical studies. *Gastroenterol Hepatol Bed Bench* 2013;6:14–17.
 - 53 Lai PSM, Mohd Mudri S, Chinna K, *et al.* The development and validation of the advance care planning questionnaire in Malaysia. *BMC Med Ethics* 2016;17:61.
 - 54 et alLim M, Lai P, Wong P. Cross cultural adaptation and validation of the Malay advance care planning questionnaire. *Malaysia Australasian Pharmaceutical Science Association (APSA) Annual Conference*, Adelaide, 2018.
 - 55 Goodies M. Official random number generator, 2017. Available: https://www.mathgoodies.com/calculators/random_no_custom
 - 56 Sperandei S. Understanding logistic regression analysis. *Biochem Med* 2014;24:12–18.
 - 57 Chu L-W, Luk JKH, Hui E, *et al.* Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong. *J Am Med Dir Assoc* 2011;12:143–52.
 - 58 Ng QX, Kuah TZ, Loo GJ, *et al.* Awareness and attitudes of community-dwelling individuals in Singapore towards participating in advance care planning. *Ann Acad Med Singap* 2017;46:84–90.
 - 59 Chu LW. One step forward for advance directives in Hong Kong. *Hong Kong Med J* 2012;18:176–7.
 - 60 Advance Care Planning. Decision making for the end of life: Hospis Malaysia, 2017. Available: <https://hospismalaysia.org/wp-content/uploads/2017/02/Advance-Care-Planning.pdf> [Accessed 20 Apr 2020].
 - 61 Advance Care Planning Advisory Services. ACGConcept, 2015. Available: <https://www.agedcare.com.my/acp-advisory/> [Accessed 20 Aug 2021].
 - 62 Singapore MoH. Advance medical directive, 2019. Available: <https://www.moh.gov.sg/hpp/all-healthcare-professionals/guidelines/GuidelineDetails/advance-medical-directive> [Accessed 01 Jan 2020].
 - 63 Dobbs D, Park NS, Jang Y, *et al.* Awareness and completion of advance directives in older Korean-American adults. *J Am Geriatr Soc* 2015;63:565–70.
 - 64 Yonashiro-Cho J, Cote S, Enguidanos S. Knowledge about and perceptions of advance care planning and communication of Chinese-American older adults. *J Am Geriatr Soc* 2016;64:1884–9.

- 65 Bowman KW, Singer PA. Chinese seniors' perspectives on end-of-life decisions. *Soc Sci Med* 2001;53:455–64.
- 66 Ko E, Berkman CS. Advance directives among Korean American older adults: knowledge, attitudes, and behavior. *J Gerontol Soc Work* 2012;55:484–502.
- 67 Ng R, Chan S, Ng TW, *et al.* An exploratory study of the knowledge, attitudes and perceptions of advance care planning in family caregivers of patients with advanced illness in Singapore. *BMJ Support Palliat Care* 2013;3:343–8.
- 68 McCarthy J, Weafer J, Loughrey M. Irish views on death and dying: a national survey. *J Med Ethics* 2010;36:454–8.
- 69 Jeong S, Ohr S, Pich J, *et al.* 'Planning ahead' among community-dwelling older people from culturally and linguistically diverse background: a cross-sectional survey. *J Clin Nurs* 2015;24:244–55.
- 70 Johnstone M-J, Kanitsaki O. Ethics and advance care planning in a culturally diverse Society. *J Transcult Nurs* 2009;20:405–16.
- 71 Biondo PD, Kalia R, Khan R-A, *et al.* Understanding advance care planning within the South Asian community. *Health Expect* 2017;20:911–9.
- 72 Lee MC, Hinderer KA, Kehl KA. A systematic review of advance directives and advance care planning in Chinese people from eastern and Western cultures. *Journal of Hospice & Palliative Nursing* 2014;16:75–85.
- 73 Ohr S, Jeong S, Saul P. Cultural and religious beliefs and values, and their impact on preferences for end-of-life care among four ethnic groups of community-dwelling older persons. *J Clin Nurs* 2017;26:1681–9.
- 74 Kwon I, Hattori K, Lee K-bong, *et al.* End-Of-Life decisions: a survey of the perspectives of people in Korea, China, and Japan. *Acta Bioeth* 2015;21:173–82.
- 75 Davison SN. End-Of-Life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 2010;5:195–204.
- 76 Gallagher J, Bolt T, Tamiya N. Advance care planning in the community: factors of influence. *BMJ Support Palliat Care* 2020. doi:10.1136/bmjspcare-2020-002221. [Epub ahead of print: 08 Jun 2020].
- 77 Tripken JL, Elrod C, Bills S. Factors influencing advance care planning among older adults in two socioeconomically diverse living communities. *Am J Hosp Palliat Care* 2018;35:69–74.
- 78 Barwise A, Juhn YJ, Wi C-I, *et al.* An individual Housing-Based socioeconomic status measure predicts advance care planning and nursing home utilization. *Am J Hosp Palliat Care* 2019;36:362–9.
- 79 Jahn Kassim P, Alias F. Advance directives for medical treatment: the current legal status. *Malayan Law Journal* 2015;3:i–xx.
- 80 Embong AR. Malaysia as a multicultural Society, 2002. Available: <https://digitalcommons.maclester.edu/macintl/vol12/iss1/10>
- 81 Ahmad Z. Multiculturalism and Religio-ethnic plurality. *Cult Relig* 2007;8:139–53.