

Awareness and Attitudes of Community-Dwelling Individuals in Singapore towards Participating in Advance Care Planning

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Abstract

Introduction: Advance care planning (ACP) is an important aspect of end-of-life care that has been shown to improve patient autonomy in decision-making and reduce stress for surviving family members. Given the rapidly ageing population in Singapore, a greater emphasis on end-of-life care planning is needed. This study therefore sought to examine the awareness and attitudes of the general Singaporean community towards participating in ACP, which are not known hitherto. **Materials and Methods:** A 24-item interviewer-administered questionnaire was constructed and administered via door-to-door survey amongst community-dwelling residents living in Housing and Development Board (HDB) flats across Singapore, selected via a two-stage stratified random sampling. **Results:** Of the 406 completed surveys, 14.4% of respondents had heard of ACP (n = 58), mostly through the media (67.9%), from family and friends (21.4%) and healthcare providers (21.4%). Only 26.8% of those who had previously heard of ACP knew how to begin an ACP discussion and 12.5% of them had a prior ACP discussion. After education, the majority of respondents were willing to begin an ACP discussion (n = 236, 60.1%). Being of an older age, having a life threatening illness, and having more knowledge about ACP were significant factors associated with willingness to have an ACP discussion. Barriers included perceiving oneself as still healthy and preferring the family to make decisions instead. **Conclusion:** There is a low awareness but high expressed willingness to engage in an ACP discussion amongst the Singaporean community. More efforts are needed to educate the public about ACP, engage the family unit and correct the present misconceptions.

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Introduction

Advance care planning (ACP) involves discussions between healthcare professionals, patients and their families or carers about the patient's wishes and future healthcare plans. ACP is a significant aspect of end-of-life care that is associated with improved physical and emotional outcomes for both the patient as well as their loved ones.¹ The Agency for Integrated Care (AIC) first piloted ACP in Tan Tock Seng Hospital in 2009² before implementing it as a nationwide programme in 2011. Despite advocacy efforts, ACP is not widely practised in the local context.³

There remains a paucity of Asian studies examining the barriers and other issues related to ACP uptake, possibly because ACP was implemented only recently in the region. Besides, there are perceived cultural taboos unique to Asia

regarding death. Of the few local studies available on the subject of end-of-life care, the focus was primarily on other issues such as the Advance Medical Directive (AMD).⁴ This study therefore seeks to: 1) investigate the awareness of the local Singapore community towards ACP; 2) ascertain their willingness to engage in ACP discussions; and 3) identify factors that affect an individual's willingness to participate in ACP (topics that have not been studied hitherto).

Materials and Methods

In this cross-sectional study, a 24-item interviewer-administered questionnaire was developed and administered via door-to-door survey amongst community dwellers of Housing and Development Board (HDB) flats in Singapore. The residents were selected via a two-stage stratified random

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sampling within the 5 zones of Singapore, as defined by the local Urban Redevelopment Authority, namely, North, North-East, West, East and Central.⁵ Surveys within each zone were conducted via a two-stage sampling design. Briefly, a list of all the residential estates in each zone was obtained and random sampling was employed to select one residential estate in each of the 5 zones. The 5 randomly-selected estates were: Sembawang (North), Punggol (North-East), Pasir Ris (East), Marine Parade (Central), and Jurong East (West). A list of all the HDB blocks located within each selected estate was then compiled and random sampling without replacement was employed to generate the order of blocks visited. Within each selected block, random sampling without replacement was employed to generate the order of floors visited. Within each floor, the household with the highest unit number was visited first, and subsequent households were visited in descending order of unit numbers.

The inclusion criteria for the study were: 1) Singapore citizen or permanent resident; 2) at least 21 years of age; 3) proficient in English or Mandarin; and 4) ability to provide informed consent.

The questionnaire was developed with reference to the current literature,⁶⁻¹⁰ and under the guidance of domain experts in palliative medicine and public health. The questionnaire included 23 close-ended questions that evaluated the respondent's awareness and knowledge of ACP, willingness to engage in ACP, factors influencing his/her willingness to undergo an ACP discussion and demographic items (Fig. 1). If the respondent was not

previously aware of ACP, or if the respondent was previously aware of ACP but had not yet begun his/her ACP discussion, an official illustration created by AIC (<http://livingmatters.sg/health-care-professionals/>) was used to educate him/her about ACP. The respondent's willingness to begin an ACP discussion was assessed following this. At the end of the questionnaire was a free-response question to allow additional comments regarding ACP. The questionnaire was designed to take only 10 to 15 minutes to complete to avoid respondent fatigue.

The survey was administered in either English or Mandarin. The questionnaire was constructed in English and translated into Chinese, before being back-translated by an independent language teacher proficient in both languages and checked by the team for semantic equivalence. The questionnaire was also refined through pilot study with 40 random community-dwelling individuals. The aim of the pilot was to refine the wording of the questionnaires. Amendments were made based on feedback from the respondents.

Based on the results of our pilot study (17.1% awareness out of 40 random community-dwelling individuals surveyed), we postulated that the awareness of ACP in the local community was approximately 20%. A precision-based approach was then employed for sample size calculation. Adopting a 4% margin of error and assuming a 95% confidence level, an estimated sample size of 400 was anticipated.

The questionnaires were administered by 40 fourth-year medical students from the Yong Loo Lin School of Medicine, National University of Singapore (NUS). All interviewers underwent standardised interviewer training. The study protocol was approved by the local Institutional Review Board at the National University of Singapore (NUS IRB B-15-245). Verbal consent was obtained from all respondents who were provided with a participant information sheet (PIS).

All survey responses were recorded on a secure online platform. The responses were then tabulated and analysed. For continuous variables (e.g. age), the means between subgroups of interest were compared using independent sample t-tests if a normal distribution could be assumed. Means and standard deviations were reported for t-tests. Differences in proportions involving categorical variables were compared using chi-square (χ^2) tests or the Fisher's exact tests where appropriate. We summarised the association between categorical variables using frequencies and percentages, and all statistical analyses were conducted using SPSS v23.0 (IBM Corp, Armonk, NY, USA), assuming a two-sided test with 5% level of significance.

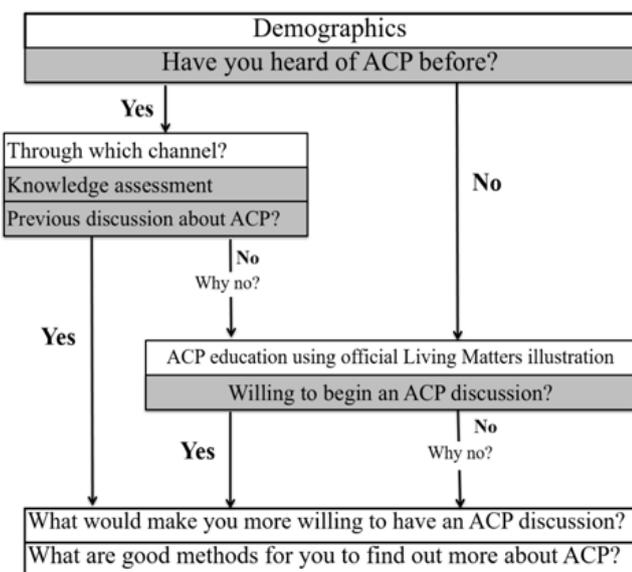


Fig. 1. Outline of the flow of questions.

Table 1. Respondents' Demographics (n = 406)

Characteristics	Respondents ^a	Population Census 2010 ^b
		(%)
Male, n (%)	190 (46.9)	49.3
Age (years), mean (SD)	46.8 (16.3)	
Occupation, n (%)		
Unemployed/retired	114 (28.4)	-
Employed	288 (71.6)	
Occupation, n (%)		
Non-healthcare	394 (98.0)	-
Healthcare	8 (2.0)	-
Marital status, n (%)		
Married	296 (73.1)	59.4
Single/divorced/widowed	109 (26.9)	40.6
Race, n (%)		
Chinese	273 (67.4)	74.1
Malay	64 (15.8)	13.4
Indian	53 (13.1)	9.2
Others	15 (3.7)	3.3
Nationality, n (%)		
Singapore citizen	351 (86.5)	85.7
Singapore permanent resident	55 (13.5)	14.3
Religion, n (%)		
Christianity, including Catholics	80 (19.7)	18.3
Buddhism	95 (23.4)	33.3
Taoism	28 (6.9)	10.9
Islam	71 (17.5)	14.7
Hinduism	40 (9.9)	5.1
No religion	92 (22.7)	17.0
Other religions	0 (0.0)	0.7
Religion, n (%)		
Yes	314 (77.3)	83.0
No	92 (22.7)	17.0
Highest qualification, n (%)		
Primary school and below	62 (15.3)	32.4
Secondary	86 (21.2)	18.9
Post-secondary, non-tertiary	52 (12.8)	11.1
Diploma and professional qualifications	94 (23.2)	14.8
University	112 (27.6)	22.8
Housing type, n (%)		
1-room flat or 2-room flat	21 (5.2)	4.6
3-room flat	57 (14.0)	20.0
4-room flat	189 (46.6)	31.9
5-room flat, executive flat	139 (34.2)	25.6
Condominium, landed property	0 (0.0)	16.9
Others	0 (0.0)	0.7

^aNot all values tally to 406 because of responses withheld by respondents.
^bReference made to Census of Population 2010 Statistical Release 1.

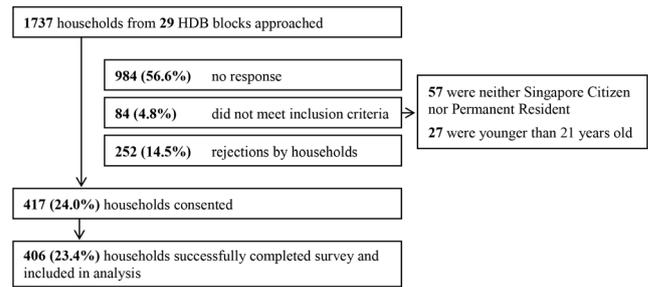


Fig. 2. Response rate.

Results

A total of 1737 household units from 29 HDB blocks were approached and the response rate is summarised in Fig. 2. The demographic attributes of our study respondents were largely similar to the population distribution of the 2010 Singapore Population Census (Table 1). A similar proportion of male and female respondents were present (46.9% and 53.1%, respectively), and the average age of our cohort was 46.8 (SD 16.2) years. Majority of our study respondents were Chinese (67.4%), followed by Malay (15.8%), Indian (13.1%) and other ethnicities (3.7%).

Awareness of the Local Singapore Community towards ACP

Fifty-eight respondents (14.4%) reported having previously heard of ACP. Respondents who were previously aware of ACP were more likely to be older (50.8 years vs 46.2 years, $P = 0.045$, $t = 2.0$, $df = 402$), Singaporean (94.8% vs 85.0%, $P = 0.043$, $\chi^2 = 4.1$, $df = 1$), and tended to make important personal decisions on their own (51.7% vs 33.0%, $P = 0.021$, $\chi^2 = 7.8$, $df = 2$) as compared to those who have not heard about ACP. Prior awareness of ACP was not associated with gender, ethnicity, occupation, marital status, nationality, religion, educational qualification, housing type, financial status and the presence of medical illness.

Majority of the individuals who have heard about ACP received the information from the media (67.9%), their family and friends (21.4%), healthcare providers (21.4%), ACP advocates (3.6%) and other sources (8.9%) such as their workplace, during a seminar and from hospital-based advertising.

These respondents were then assessed on their knowledge about ACP using 4 true-false statements (Table 2) (the 1st and 2nd statements in Table 2 are incorrect). Among the 56 individuals from whom responses were obtained for this question, 11 respondents (19.6%) answered all 4 statements correctly, while 15 respondents (26.8%) answered 3 out of 4 statements correctly, 22 respondents (39.3%) answered 2 out of 4 statements correctly, 6 respondents (10.7%) answered 1 out of 4 statements correctly and 2 respondents (3.6%) answered all 4 statements incorrectly. Notably, there was

Table 2. Respondents' Knowledge of ACP (Amongst Those Who Have Heard of ACP Previously) (n = 56)

	Respondents Correctly Identifying Statement As True/False, n (%)
ACP allows me to share my beliefs and values*	48 (85.7)
ACP is an ongoing process and I can change my decisions anytime*	41 (73.2)
ACP requires payment†	33 (58.9)
ACP is a legally binding document†	17 (30.4)

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*True statement.

†False statement.

Table 3. Reasons for Unwillingness to Begin an ACP Discussion (Amongst Those Who After ACP Education Were Unwilling to Begin Discussion) (n = 157)

Reason	Respondents, n (%)
I am still healthy	55 (35.0)
I find that an ACP is unnecessary	22 (14.0)
I would like my family to make the decisions for me	14 (8.9)
I still don't know enough about the ACP	13 (8.2)
I find it difficult/uncomfortable to discuss ACP topics	9 (5.7)
I do not know how to begin an ACP discussion	8 (5.1)
An ACP discussion is too troublesome	8 (5.1)
My family discourages me from making an ACP	3 (1.9)
Others	
No spare time for ACP discussion	7 (4.5)
ACP is not a priority	4 (2.5)
Unsure about usefulness since not legal binding	3 (1.9)
Believes having medical insurance is sufficient	2 (1.3)
Do not wish to discuss with an outsider	2 (1.3)
Religious and ethical considerations	2 (1.3)
Believes something similar has been done already	1 (0.6)
Missing response	4 (2.5)

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no association between the respondents' knowledge scores and the channels through which they had learnt about ACP.

Seven (12.5%) of these 56 respondents had a previous discussion regarding their ACP. Respondents who were more likely to have had a previous ACP discussion were those who had answered "yes" to knowing how to begin an ACP discussion (71.4% vs 20.4%, $P = 0.012$). Amongst the 49 respondents who did not have a previous ACP discussion, the top 2 reasons cited for not initiating a discussion was they still felt healthy (40.8%) and they did not know how to begin an ACP discussion (28.6%).

Willingness to Engage in ACP Discussions and Factors that Affect an Individual's Willingness to Participate in ACP

The majority of respondents (n = 348) had not previously heard of ACP before. We briefly explained ACP using a comic illustration from AIC to this group of respondents, as well as those who had previously heard of ACP but did not have a prior ACP discussion (n = 51). Of the 393 respondents who successfully received this brief education on ACP, 236 (60.1%) were willing to begin an ACP discussion post-education. Those who were willing to begin an ACP discussion were more likely to be receiving financial support from their family (40.7% vs 30.6%, $P = 0.042$, $\chi^2 = 4.1$, $df = 1$). There was also a trend towards those who tend to make important personal decisions together with their family (60.4% vs 48.4%, $P = 0.051$, $\chi^2 = 6.0$, $df = 2$) and those with university or higher education qualification (31.8% vs 21.0%, $P = 0.051$, $\chi^2 = 9.4$, $df = 4$) were also more likely to have greater willingness to begin an ACP discussion.

The reasons given by those who were unwilling to begin an ACP discussion are presented in Table 3. The top 3 reasons for being unwilling to begin an ACP discussion after learning more about ACP were: "I am still healthy" (35.0%), "I find that an ACP is unnecessary" (14.0%) and "I would like my family to make that decision for me" (8.9%).

All 406 respondents, regardless of whether they have heard of ACP prior to the survey, were asked what would make them more willing to have a discussion about ACP. Common factors listed by respondents were having a serious life threatening illness (83.7%), if the respondent knew more about ACP (76.8%) and if the respondent was at an older age (74.6%) (Table 4).

The top 3 methods which respondents perceived as good methods for learning more about ACP were advertisements in the media (86.9%), general practitioners or other healthcare providers advocating ACP (70.4%) and brochures given out by the government (62.6%).

Discussion

ACP may be understood as a process of health behaviour change.⁷ We recognise that the survey respondents had varying levels of readiness, willingness, and different perceived barriers and benefits for participating in ACP. This suggests the utility of tailored, stage-specific interventions to improve ACP uptake. The overall low awareness and lack of knowledge regarding ACP in this study reflect a sizeable pre-contemplative population in the local community. This parallels other studies done in Australia,⁸ Malaysia⁹ and China¹⁰ that have shown similar findings of low awareness of ACP in their respective populations. Evidently, more efforts should be directed towards educating the general public about ACP and its unique benefits (Fig. 3).

Table 4. Factors That Would Make Respondents More Willing to Have a Discussion About ACP (n = 406)

Option	Respondents, n (%)
If I have a serious life threatening illness	340 (83.7)
If I know more about ACP	312 (76.8)
When I'm at an older age	303 (74.6)
If the ACP is easily accessible for me to do	298 (73.4)
If my doctor talks to me about my ACP/initiates a conversation about the ACP	276 (68.0)
If I can choose who is present and who accompanies me in the discussion	266 (65.5)
If I know of someone who has done an ACP	242 (59.6)
If some financial incentives were given to me	203 (50.0)
Others	
Have more spare time for discussion	3 (0.7)
Knowledge of the benefits of ACP	3 (0.7)
Relevant anecdotal sharing	3 (0.7)
ACP is made legal	2 (0.5)
Door-to-door promotion and surveys	2 (0.5)
Doctor is willing to talk about it and is passionate	1 (0.2)
Family is supportive	1 (0.2)
Family member raises it up	1 (0.2)
Government arranges transport to attend ACP courses	1 (0.2)
More advertisement and emphasis	1 (0.2)

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These educational interventions should be angled towards factors that would increase one's willingness to do an ACP. As with most processes of behaviour change, while knowledge of ACP is a prerequisite for changing behaviour, it in itself is insufficient to achieve this change as motivation is a critical determinant.¹¹

In this study, being of an older age (74.6%) and having a serious life threatening illness were significant motivating factors to begin an ACP discussion (83.7%). This is commonly seen in several other studies where ACP was described as unnecessary, inappropriate, premature, and unrealistic for those without a serious or life threatening disease.¹²⁻¹⁵ Whilst it can be argued that the process of ACP is less relevant for younger and healthier individuals, in reality, life can be unpredictable and an ACP is intended to be a continuing process that will evolve over time.

Therefore, we suggest 3 platforms for public education about ACP, namely the media, healthcare professionals, and engaging the family unit.

The Media

Our study found no association between the respondents' knowledge scores and the channels through which they had learnt about ACP. This suggests that learning about ACP from the media, healthcare providers, ACP advocates, and family and friends may be equally useful. However, most of our study respondents cited media as an effective modality to learn more about ACP and most respondents who had previously heard of ACP learnt of it through the media. This finding is corroborated with a previous study in Singapore regarding knowledge of AMD, where media was found to play an important role in disseminating information about end-of-life issues.⁴

Healthcare Professionals

Majority of our respondents felt that healthcare personnel would be good channels to learn more about ACP. This finding parallels a 2012 qualitative study on 23 Korean American older adults,¹² in which most respondents preferred their physician to initiate an end-of-life discussion. However, only 22.2% of our survey respondents who had

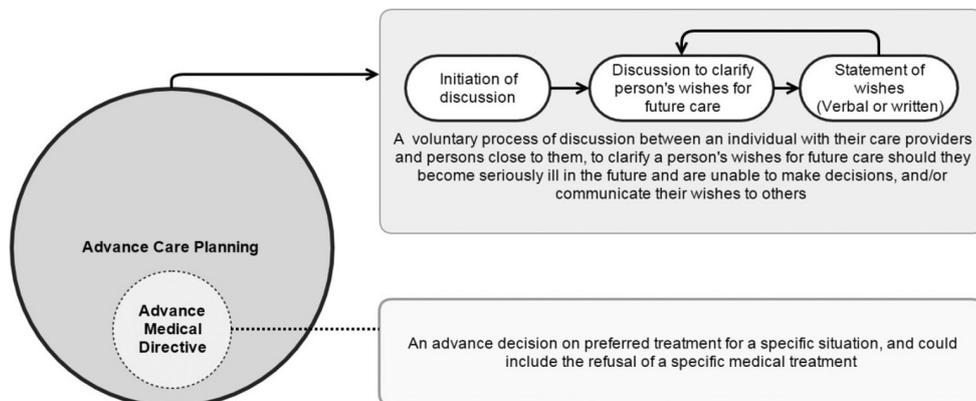


Fig. 3. Pictorial representation of advance care planning (ACP).

previously heard of ACP learnt of it through this manner. A local study conducted in 2011 found that lack of time, concerns regarding unhappiness from the family, and the perception that patients were not prepared to discuss about end-of-life preferences were barriers for physicians towards initiating an ACP discussion.¹⁶ Another United Kingdom study in 2009 involving healthcare professionals revealed a lack of agreement as to whose responsibility it was to initiate ACP discussions and the setting in which it should be discussed.¹⁷

It is thus important to clarify and reaffirm the role of healthcare professionals in initiating ACP discussions, and educate them on the ACP process and the communication skills needed so they feel better equipped to discuss such matters. Individuals might not understand the clinical implications of their care and treatment preferences, and physicians are well positioned to clarify issues and provide adequate and sufficient medical or healthcare information. Timely referral to a trained ACP facilitator can also be made. ACP is akin to quality clinical encounters in medicine; physicians have a key but not an all-encompassing role.

Engaging the Family Unit

Currently in Singapore, ACP is being implemented in the majority of tertiary hospitals in selected departments, such as geriatrics or palliative care. As ACP is usually done in the presence of an individual's family members and loved ones, a potential approach would be to engage not only patients but also to extend the ACP discussion to their family members. Facilitators can utilise this opportunity to invite the patient's family members to begin ACP discussions of their own. A local study¹⁵ found that involving the family early in ACP discussions was commonly cited as key for successful ACP. Conversely, a lack of enthusiasm from the family posed as a significant barrier to ACP discussions.

Finally, it is important to discuss the limitations of this study. Firstly, non-English and non-Mandarin speaking residents, as well as residents living in private estates were excluded (but less than 20% of Singapore's population live in private estates¹⁸). Secondly, the poor participatory response in this study could be attributed to the fact that several Asian cultures, especially the Chinese, consider discussions surrounding end-of-life issues as taboo; as such, people might have refused to take part in our survey due to the taboo subject matter. Similarly, those who agreed to participate in our survey may generally be more receptive to talking about end-of-life issues than those who declined. Moreover, social desirability bias may have influenced the respondents' willingness to engage in an ACP discussion after education. This could have compromised the validity of the findings. Further studies should consider recruiting a larger number of participants from both public and private

households, especially those who speak different languages. This will allow a better representation of Singapore's population and improve the validity of the results.

This is the first study of its kind specific to Singapore. A recommendation for future studies would be to validate the questionnaire used and include a qualitative component that will provide greater insight into the mindsets and attitudes of respondents. Focus group and in-depth interviews will be able to capture views not measured by our questionnaire.

Conclusion

This study found overall low awareness of ACP but high expressed willingness to engage in an ACP discussion after education. Lack of awareness of ACP is a factor contributing to current low uptake rates albeit there could be other factors. In formulating an effective approach to ACP education, possibilities include utilising media platforms, training healthcare providers on ACP administration and clarifying their role in it, and closely involving the family unit at each stage during ACP discussions.

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