

## Knowledge, Attitudes and Practices of the Advance Medical Directive in a Residential Estate in Singapore

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### Abstract

**Introduction:** This study investigates the knowledge, attitudes and practices of residents in a residential estate in Singapore on the Advance Medical Directive (AMD). **Materials and Methods:** A community-based cross-sectional study was conducted with residents in the residential estate of Toa Payoh Lorong 6, Singapore. A stratified random sampling was conducted to obtain a representative sample of the estate. Only residents aged 21 years and older were included. An interviewer-administered questionnaire was conducted, and only those who understood the AMD sufficiently were further evaluated on their knowledge, attitudes and practices. **Results:** A total of 414 residents were enrolled (50.1% response rate). Only 37.9% of the participants knew about the AMD prior to this study. Participants who had a higher knowledge level of AMD, did not wish “for an artificially prolonged life”, “to be kept alive indefinitely on a life-support machine”, wished to “lessen the financial burden of loved ones”, “avoid prolonged suffering” and accepted the “imminence of death” were more willing to sign an AMD. However, “religious beliefs”, “personal ethical views”, “dissuasion by family members” and “unclear terminology in the AMD” discouraged the participants from signing an AMD. After adjusting for significant factors, participants who did not wish “to be kept alive indefinitely on a life-support machine” and accepted the “imminence of death” were found to correlate significantly with the willingness to sign an AMD [Prevalence Rate Ratio (PRR) = 2.050 [1.140-3.685],  $P = 0.016$ ; PRR = 2.669 [1.449-4.917],  $P = 0.02$ , respectively]. **Conclusions:** There is a need to increase awareness on the AMD. Public education methods can be improved to inform residents on the implications of the AMD.

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**Key words:** Decision making, Predictors

### Introduction

The Advance Medical Directive (AMD) Act was passed in Parliament in May 1996. The AMD is a legal document that an individual can sign in advance to inform his or her attending doctor that he or she does not want any extraordinary life-sustaining treatment to be used to prolong life in the event that he or she becomes terminally ill or unconscious. Anyone currently residing in Singapore, is of at least 21 years of age, and of a sound mind can sign an AMD. The signing must be witnessed by 2 people, one of whom must be a doctor. The AMD can be revoked at any time, in the presence of a witness. Currently, the medical personnel caring for the patient are not allowed to enquire whether he or she has made or intended to make a directive.<sup>1</sup> However, they are still allowed to discuss the issue of signing an AMD with their patients.

In recent years, the AMD has been the subject of much public discussion and debate, in light of Singapore’s ageing population, end-of-life planning and other related issues.

Despite this, the AMD is not known by many Singaporeans. To date, less than 10,000 people in Singapore have opted to sign an AMD. In contrast, there is a greater awareness of advance directives in other countries.<sup>2-4</sup> Limited work has been conducted locally to gather information on perspectives towards AMD, and to elucidate possible reasons for the low take-up rate. To our knowledge, there are no reports on the knowledge, attitude and practices (KAP) of AMD among residents of Singapore. While overseas studies have been conducted, it is difficult to apply their findings to our local context. This is largely because Singapore’s ethnic and religious makeup is significantly different from that of the United States,<sup>5,6</sup> the Netherlands,<sup>7</sup> India<sup>8</sup> and Malaysia,<sup>9</sup>

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to name a few.

It is with this view that a group of undergraduate medical students at the National University of Singapore (NUS) conducted a study under the Department of Epidemiology and Public Health. The objectives of the study were to assess the knowledge, attitudes and practices of AMD in the community of Toa Payoh, Singapore, and the factors that may affect one's willingness to sign it.

## Materials and Methods

This was a cross-sectional, community-based study in Toa Payoh Lorong 6, Singapore. Addresses were selected via a stratified random sampling to obtain a representative sample of the residential estate. Any resident of at least 21 years of age was eligible and an interviewer-administered questionnaire was used at the resident's home.

After demographic information was collected, a first round of knowledge assessment was conducted. Any outcome to this was followed by a standardised educational intervention from a fact sheet and a second round of assessment was made. A fail resulted in another round of educational intervention and if the person failed the third assessment, the person was not evaluated further.

The questionnaire comprised 4 sections – personal demographics, knowledge, attitudes and practices. The first section collected demographical data and assessed awareness of AMD. In the second section, knowledge was tested, before and after educational intervention(s), with 6 questions with a True/False/Don't know response. A fail was defined as a score less than 7. The third and fourth section assessed attitudes towards AMD, and recommendations for the AMD respectively. These required a response either on a scale from 1 (strongly disagree) to 6 (strongly agree) or a Yes/No answer.

Non-responders were defined as people who refused to participate in the survey after a face to face meeting by the interviewer while non-contactables were defined as those who did not answer their doors after 3 attempts on separate days at different times.

The interviewers had training and practice sessions prior to the interview. The study had earlier been cleared by the National University of Singapore, Institutional Review Board Reference Code 08-362.

### Data Analysis

Data were analysed using a computer-based software package - the Statistical Package for the Social Sciences (Version 16.0).

For the knowledge questions (Section 2 of questionnaire), marks were allocated as follows: 2 marks for a correct answer, 1 mark for an unsure answer and 0 marks for an incorrect answer. Equal weightage was given to each

question as all were of equal importance to the understanding of the AMD. The range of possible knowledge scores were from 0 to 12.

Comparison of ordinal data was done using non-parametric tests such as the Wilcoxon sign-ranked test. Categorical variables were compared using Pearson's chi-square test and Fisher's exact test. A proportional hazards regression analysis adopted for cross-sectional data was done to analyse positive and negative factors for causing someone to be willing to sign/not sign an AMD. Factors adjusted for were final knowledge score, feeling that "passing away naturally from a terminal illness was better than an artificially prolonged life", not wishing to be "kept alive indefinitely on a life-support machine", wishing to "lessen the financial burden of loved ones", "avoid prolonged suffering", accepting the "imminence of death when you have an incurable terminal illness", "religious beliefs", "personal ethical views", "dissuasion by family members" and "unclear terminology".  $P < 0.05$  was considered statistically significant.

## Results

### Demographic Data

Out of a total of 1200 randomly selected households, there were 414 responders, 398 non-responders and 388 non-contactables, resulting in a response rate of 50.1%. Table 1 shows the demographic attributes of those who participated in the survey.

### Knowledge

Only 37.9% (150) of our sample population had heard of the AMD prior to this study. Of those who had, 65.8% (96) learnt of AMD from the newspapers, 17.8% (26) from the television, 4.0% (6) from their family doctors, 1.4% (2) from their relatives and 11.0% (16) cited other sources.

The median knowledge score on the first attempt was 6, and this was significantly increased to 10 for the second attempt after educational intervention. This suggests that education effectively increases an individual's knowledge of AMD. Of the participants, 91.5% (371) passed the education assessment.

### Attitudes

Out of those who passed the assessment, 60.6% (225) were willing to sign an AMD, 84.7% (309) thought that AMD was beneficial, and 70.6% (259) felt that it was relevant to them. Of those who thought the AMD was irrelevant, the reasons given were that that it was bad luck to talk about death (17.4%), that they were too young to be concerned about death (38.9%) and that they were unlikely to be in a situation that required an AMD (51.8%). There is a positive association between the final knowledge score and the

Table 1. Demographic Factors of the Participants

	No.	%		No.	%
Respondents	406	100.0			
Gender			Marital status		
Male	186	46.9	Single	108	26.7
Female	211	53.1	Married	260	64.4
			Widowed	16	4.0
			Divorced	20	5.0
Age (y)			Chronic disease		
21-30	66	16.4	Yes	140	34.9
31-40	71	17.6	No	261	65.1
41-50	88	21.8			
51-60	75	18.6	Education		
61-70	60	14.9	No formal education	36	8.9
71-80	32	7.9	Primary and Secondary education	218	54.0
81-90	10	2.5	Tertiary education	150	37.1
91-100	1	0.2			
Ethnicity			Citizenship		
Chinese	313	78.1	Singaporean	360	90
Malay	37	9.1	Permanent Resident	34	8
Indian	41	10.1	Foreigner	10	3
Others	8	2.4			
Religion			Housing type		
Yes	326	80.7	1 room	7	1.7
No	78	19.3	2 room	121	30.0
			3 room	129	32.0
Buddhism	129	38.9	4 room	56	13.9
Christianity	96	28.9	5 room	88	21.8
Hinduism	39	11.7	Executive	2	0.5
Islam	43	13.0			
Taoism	17	5.1			

NB: Some numbers do not add up to 100% due to missing data.

willingness to sign an AMD ( $P = 0.07$ ).

We explored the effects of family influences and views on dying on the attitudes of respondents towards signing an AMD. When exploring family influences, it was found that 41.5% (154) had someone close with a terminal illness and 13.0% (48) had discussed the issue of AMD with their families. However, these were not significant factors in the signing of an AMD ( $P = 0.574$ ;  $P = 0.063$ , respectively). What stopped people from discussing the issue of AMD with their families was the lack of adequate knowledge on the AMD (63.2%), that they had never thought about death (36.5%) and that it was bad luck to talk about death (88.5%).

When asked on their view of dying, 87.0% (322) felt that “passing away naturally from a terminal illness was better

Table 2. Association between Factors and Willingness to Sign an AMD

Factors	Prevalence Rate Ratio (95% CI)	P
Family background		
Someone close with terminal illness	1.05 (0.889-1.236)	0.315
Had prior discussion with the family	1.24 (0.987-1.468)	0.063
Views on death		
Belief that passing away from a terminal illness is better than an artificially prolonged life	1.44 (1.034-2.007)	0.011
Do not want to be kept alive indefinitely on a life-support machine	2.42 (1.586-3.985)	<0.001
Persuading factors cited for signing the AMD		
Wish to lessen financial burden	1.381 (1.026-1.860)	0.011
Wish to lessen emotional burden	1.342 (0.991-1.817)	0.073
Wish to avoid prolonged suffering	2.102(1.653-2.673)	<0.001
Acceptance of death in terminal illness	2.396 (1.922-2.988)	<0.001
Dissuading factors cited for not signing the AMD		
Inconvenience	1.074 (0.731-1.727)	0.122
Religious beliefs	0.681 (0.524-0.885)	0.005
Personal ethics	0.513(0.403-0.654)	<0.001
Family members	0.639 (0.495-0.824)	0.029
Mistrust in doctors	0.923 (0.694-1.227)	0.061
Unclear terminology	0.771(0.596-0.998)	0.001

AMD: Advance Medical Directive

than an artificially prolonged life”, and 87.1% (323) would not want to be “kept alive indefinitely on a life-support machine”, and these were significant factors that affected one’s willingness to sign the AMD ( $P = 0.011$ ;  $P < 0.001$ , respectively) (Table 2).

The dissuading and persuading factors for why someone would be willing to sign an AMD were investigated. Dissuading factors surveyed were that of inconvenience (40.2%), religious beliefs (20.6%), personal ethical principles (33.6%), family members (44.0%), distrust of doctors (24.9%) and unclear terms (51.5%). Personal ethics ( $P < 0.001$ ), the views of family members ( $P = 0.029$ ), having religious beliefs ( $P = 0.005$ ), and unclear terminology of the AMD ( $P = 0.001$ ) were significant factors in preventing responders from signing an AMD. Inconvenience ( $P = 0.122$ ) and lack of trust in doctors ( $P = 0.061$ ) were found to be insignificant dissuading factors (Table 2).

Persuading factors surveyed were that of lessening the financial burden on loved ones (85.0%), lessening the emotional burden on loved ones (85.3%), avoiding prolonged suffering (89.6%) and facing the imminence of

Table 3. Analysis of Significant Factors after Adjustment for Other Possible Confounding Factors

Adjusted factors*	Prevalence Rate Ratio (95% CI) for willingness to sign AMD	P
Do not want to be kept alive indefinitely on a life-support machine	2.050 (1.140-3.685)	0.016
Imminence of death	2.669 (1.449-4.917)	0.02

\*see data analysis section

death in the event of a terminal illness (86.3%). Lessening the financial burden on loved ones, avoiding prolonged suffering and the imminence of death were significant factors in motivating responders to sign an AMD ( $P=0.011$ ;  $P<0.001$ ;  $P<0.001$ , respectively). Reducing the emotional burden on their loved ones, however, was insignificant ( $P=0.073$ ) (Table 2).

After adjusting for significant factors, there were 2 factors affecting the willingness to sign the AMD in relation to various predictor variables: Not wanting to be kept alive indefinitely on a life-support machine, and accepting the imminence of death where there is a terminal illness [PRR = 2.050 (1.140-3.685),  $P=0.016$ ; PRR = 2.669 (1.449-4.917),  $P=0.02$ , respectively] (Table 3).

### Practices

Of the respondents, 78.4% (290) saw it necessary to have a doctor present when signing an AMD. The main reasons were to provide medical knowledge (93.1%), to make the process more official (71.6%), to prevent coercion by others (43.6%) and because they are more comfortable having a doctor around (71.8%). Of those who felt that it was not necessary to have a doctor present when signing an AMD, factors cited were that of inconvenience (59.3%), cost (51.2%) and breach of confidentiality (80.2%), respectively.

About 61.0% (225) felt that their primary care doctor should raise the issue of AMD during a normal consultation and 71.5% (264) were comfortable if their attending doctor asked for their AMD status. Majority were willing to share their AMD status with their family general practitioner (GP) (81.8%), with their attending doctor (86.5%) and other healthcare providers (74.9%). Two hundred and ninety-two (79.1%) felt that the government should raise the awareness of the AMD.

## Discussion

### Knowledge

This study revealed that the awareness of the AMD was still low (37.9%) among the population surveyed. However, it is noted there was no association between demographic

factors and knowledge scores. This suggests that education on the AMD has the potential to be equally effective across all socioeconomic groups. There was an association found between the knowledge of the AMD, as reflected by higher scores, and the individual's willingness to sign. Indeed, this association between knowledge and an attitude towards support of it has been demonstrated in Singaporean GPs in a local study.<sup>10</sup> However, causality cannot be established.

### Attitudes

Lessening the financial burden, the imminence of death in the event of a terminal illness and the hope of avoiding prolonged suffering were the significant motivating factors for signing an AMD. These factors are corroborated with studies done overseas. Sahm et al<sup>11</sup> reported that the diagnosis of a life-threatening disease increased the tendency to concern oneself with treatment at the end of life. These factors would point to a need to disclose the prognosis of terminal illnesses to patients so that they can make a fully informed decision on end-of-life issues. Of course, this has to be evaluated by the attending physician on a case to case basis. A local study<sup>12</sup> has also shown that the majority of elderly patients wanted to be told of their prognosis to make adequate preparations.

On the other hand, personal ethical principles, religious beliefs, unclear terminology and inconvenience were significant dissuading factors. Several of these factors were also identified in overseas studies.<sup>13,14</sup> Understanding these barriers can help the relevant authorities to tailor awareness and accessibility to the AMD.

After adjusting for various predictor variables, it was found that the factors of not wanting to artificially prolong life indefinitely (PRR = 2.050), and accepting the imminence of death in the face of a terminal illness (PRR = 2.669) were strong predictors of a willingness to sign an AMD. It suggests that raising the awareness of the aims of the AMD with respect to terminal illness may motivate more people to sign up.

### Practices

Although 78.4% of the people surveyed saw the need for a doctor to be a signatory for the AMD, the inconvenience, unnecessary cost and possible breach of confidentiality associated with these issues are genuine concerns that many share. In total, 60.6% of responders expressed a willingness to sign the AMD, and this is corroborated by evidence from a Malaysian study<sup>9</sup> which states that "despite the lack of knowledge... respondents were very open to the concept".

A majority was willing to share their AMD status with their family GP (81.8%), with their attending doctor (86.5%) and other healthcare providers (74.9%), suggesting that current restrictions on the disclosure of the patient's AMD

status might not be necessary. However, due to limitations of study design, this needs to be explored further.

The media plays an important role in providing information about the AMD. Of the majority (79.1%) who felt that the government should raise awareness, television and newspapers (83.6%) were cited as their main sources of information on the AMD.

### Limitations

It is important to point out the limitations of this study. Firstly, due to logistical reasons, the study design was limited to a relatively small sample size. Additionally, the study design was limited to a cross-sectional study. Hence, it is to be noted that it may be difficult to assess one's attitudes and practices based on information that is just acquired, without giving one time to process or analyse it. For example, when the respondents were asked for their views on sharing their AMD status with their doctors, these respondents may not have understood the implications of sharing information with the doctor just after being educated about the AMD for the first time. Given time, they may have doubts that the standard of healthcare could be compromised due to their signing of the AMD, which Sahm et al<sup>11</sup> had found. Therefore, there might be a possible under-representation of the true number of people who could be comfortable with sharing such information.

### Recommendations

Further studies may include a prospective investigation into the perspectives of residents towards the AMD. Also, a representative sample of Singaporeans can be evaluated for their perspectives towards the AMD, so as to better serve the needs of Singaporeans in end-of-life planning.

### Conclusion

From the study, it can be concluded that there is low awareness of the AMD. However, a larger number of residents were willing to sign the AMD, with the factors of not wanting to artificially prolong life indefinitely, and accepting the imminence of death in the face of a terminal illness being highly significant predictors. The majority also felt that awareness of the AMD should be raised by the government. There may be a need to better inform the population of Singapore on end-of-life planning with particular emphasis on its clinical implications.

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