Original Article

Advance Directives among Elderly Population: A Malaysian Experience

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Abstract

Objective: As not many studies have been done on the topic of advance directives in Malaysia and it has yet to gain awareness among our population, we realised the need for a study to be done not only to delineate the prevalence and preference but also to raise the level of awareness.

Methods: In 2015, we carried out a descriptive, cross-sectional study that targeted elderly population residing in six nursing homes and two senior activity centres in Muar. Muar a.k.a "Bandar Di Raja" is a town geographically located in the north-west region of Johor state. Data was collected through a 14 item structured questionnaire which was divided into two sections; socio-demographic profile, prevalence and preference of advance directives.

Results: The response rate for this study was 50% where a total of 70 respondents out of the 150 residents participated. Non-participation was due to the exclusion criteria. 11.4% of the respondents had heard of advance directives, but none so far have an advance directive. Among the respondents, 70% of them are open to the concept of having an advance directive. For the remaining 30% that were against the use of advance directives, 38.1% of them prefer to have decisions done by the doctors. With regards to the recording of advance directives, the verbal promise was the most favored option chosen. As for the preferences for end-of-life treatment, the majority (51%) opted for comfort care with only pain medication.

Conclusion: The prevalence of advance directives in Malaysia is progressing at an extremely slow pace, but it also showed that the elderly population are receptive to the concept of an advance directive. To promote the advancement of advance directives, the level of public awareness needs to be raised through primary care centres and awareness campaigns.

Key words: Advance directives, prevalence, nursing homes

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INTRODUCTION

An Advance Directive is a statement made by a mentally competent adult stating how they wish to be treated should they, at some stage in the future, lose mental capacity.[1-3] Such directives have an ethical basis in supporting personal autonomy and self-determination.[4] Capron has stated that when a patient has a properly executed advance directives, the patient would, in theory, alleviate much of the uncertainty that often paralyzes physicians and family members (or other surrogate decision makers) and would facilitate the resolution that best reflects their true wishes regarding their care.[5-6] According to the Australian Health Ministers' Advisory Council, 2011, advance

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directives may record (1) a person's values, life goals and preferred outcomes, (2) directions about care and treatment refusals, (3) appointment of a substitute decision maker (SDM).[7]

In the US, living wills were first proposed in 1967 and were initially closely associated with the 'right to die' and euthanasia movements. However, they became more accepted when it became clear that they were an instrument for exercising autonomy rather than simply the right to die.[2,8] First sanctioned in 1976 (Natural Death Act in California in 1976), but came to particular prominence following the Cruzan case in 1990 which involved a decision about withdrawal of artificial feeding from a young woman in a persistent vegetative state.[8-11] This led to the passing of Patient Self-Determination Act (PSDA) in 1990 mandating that all Medicare-certified institution provide written information regarding patients' right to formulate advance directives.[9, 12]

Currently, 69.9% of elderly nursing home residents have made advance directives in the U.S.[13] Unlike nursing home residents in the U.S., elderly Japanese and Koreans have a less positive attitude towards the use of advance directives and show a stronger preference for relying on the decisions of physician and family members.[14-15] Studies showed that in Japan, 62% of nursing home residents are transferred to hospital for terminal care and in Korea, 84% of the decisions made in regard to advance directives are made by physicians.[16, 17] Similarly, an exploratory study done in Singapore which is closer to Malaysia both in terms of location, cultures and norms showed that about 83.7% of the subjects (sample size of 43 subjects) have never heard of Advanced Medical Directive Act.[18]

So far in Malaysia, limited studies are done on this field. One of the surveys (sample size of 15 subjects) showed that none of the respondents had ever heard of advance directives or its concept and even after learning about it, the majority were resistant to making a formal advanced directive and preferred to express their directives verbally to a family member.[19]

Furthermore, Malaysia has a diverse multi-ethnic population which creates another factor to be taken into consideration when deciding on end-of-life treatment. This has increasingly become a paramount issue to advance directives related research.[20-25] On top of that, the respective religious and philosophical traditions that come with these various ethnicities are considered to be in direct correlation with attitudes towards end-of-life decision-making.[26] Another factor that may influence the decision making would be the educational level of the subject proven by a study that demonstrated higher levels of education are associated with more positive attitudes regarding end-of-life care and communication.[27]

Objectives

In light of these factors being in play, the aim of this study is to (1) Estimate the prevalence of advance directives among nursing homes in Muar, Malaysia. (2) Identify the major factors such as gender, ethnicity, religion and educational level influencing the decision on adopting advance directives. (3) Identify the preference on the options of end-of-life treatment if it was formulated and provided for them. (4) Verify the views of senior citizens regarding acquiring an advance directive.

METHODS

This was a descriptive, cross-sectional study which was conducted in Muar, Malaysia. We chose Muar as our strategic location for the study because it is a retiree town. Muar a.k.a "Bandar Di Raja" is a town geographically located in the north-west region of Johor state. It covers an area of 2346.12 Km^2 with a population of 239,027 out of which 6,578 are between 60-69 and 5,685 are between 70-74. ≥75 years were noted to be 7,017 (Dept. of Statistics, Muar – 2010).

Sampling method: Universal sampling method was applied in this study. Our target population included in this study were senior citizens (defined as ≥60 years old) that were residing in the six nursing homes and two senior activity centres.

Study population: All the senior citizens residing in the nursing homes and senior activity centres in Muar were encouraged to participate in our study excluding those who are:

1. below 60 years of age
2. Diagnosed with neurodegenerative disorder
3. Diagnosed with psychiatric disorder
4. Terminally ill

Survey instrument: Data was collected using a structured questionnaire which was distributed to all the targeted locations. The questionnaire was self-administrated to avoid interviewers' bias. The answered questionnaire was collected on the spot itself. Cover letters were given to the nursing homes and senior activity centres before the distribution of the questionnaire with the purpose of requesting their participation in this study. Also,

informed consent was acquired from every participant.

Questionnaire design: The questionnaire which was used in this survey was based on English Medium which was translated into two extra languages namely, Mandarin and Bahasa Malaysia as we expected a large portion of the subjects to only be familiar with their mother tongue. Back to back translation was conducted to ensure consistency of the questionnaire. The questionnaire was partly adapted from a similar study carried out in Korea.[29] Some items have also been added from a study done in the US.[9] It is a 14 item questionnaire which concentrates on the prevalence, major factors influencing the decision on advance directives, views regarding acquiring an advance directive and lastly their preferences on the options available if they are interested.

The questionnaire was given to 3 different professional individuals to retest its reliability. All the 3 participants gave a feedback saying that the questions were easy to understand and relevant to the topic. It is not time-consuming since the questions are closed ended and the participants only need to circle the preferred option.

Ethical consideration: Institution Review Board (IRB) of Asia Metropolitan University, reviewed the protocol to ensure full protection of the rights of study subjects. Following the approval by IRB, NMRR (National Malaysian Research Register) registration was carried out. Upon acquiring the NMRR registration number, the questionnaires were distributed to the study subjects. A covering letter assuring confidentiality of all the information provided accompanied the questionnaire.

Data analysis: The data was first coded and interpreted by PASW Statistics Student Version 18. Data analysis included descriptive statistics which was used to describe participants' demographic characteristics, and texts, tables, graphs, percentages or mean was used to present the results.

RESULTS

Participation rate and sample size

The response rate for this study was 50% where a total of 70 respondents out of 150 residents participated in this study.

Socio-demographic characteristics of the respondents

The mean age of respondents was 71.2 years of age with an SD of 8.8. Out of 70 respondents, 55.7% were men.

Among the participants, Malay (41.4%) and Chinese (54.3%) ethnicity are dominant and followed by Islam (42.9%) and Buddhism (44.3%) being the dominant religion. Only 15.7% of the subjects had achieved the tertiary education.

Table 1. Socio demographic characteristics (n=70)

Variable	Frequency (N)	Percentage (%)
Age		
60-69	38	54.3
70-79	20	28.6
≥80	12	17.1
Gender		
Male	39	55.7
Female	31	44.3
Ethnicity		
Malay	29	41.4
Chinese	38	54.3
Indian	3	4.3
Others	0	0.0
Religion		
Islam	30	42.9
Buddhism	31	44.3
Hinduism	3	4.3
Christianity	2	2.9
Others	4	5.7
Educational Level		
No formal education	13	18.6
Primary education	19	27.1
Secondary education	27	38.6
Tertiary education	11	15.7
Total	**70**	**100**

Prevalence of advance directives

Out of the 70 participants, only 8 (11.4%) of them have heard of advance directives, and not a single one had advance directives. Of these, only five out of the eight would want to have their advance directives done if provided the service.

Factors influencing the decision on adopting advance directives

There were 49 (70%) respondents that were agreeable to having an advance directive if provided the service. As shown in Table 2, there was not much difference between females (71%) and males (69.2%) with regards to attaining an advance directive however it was noted that the participants with tertiary education and those with no formal

education were closely similar with 54.5% for the former and 53.8% for the latter. As for religion, Buddhists (77.4%) were noted to be more receptive towards having an advance directive followed by Muslims (66.7%).

Reasons against advance directives

Table 3 shows that, of those 21 respondents that chose to not require advance directives, 38.1% of them prefer to leave it to the doctors to decide rather than making their decision beforehand. While 28.6% opted to leave it up to the family and 23.8% opted to leave it up to God or fate.

Table 2. Socio-demographic characteristics affecting the choices of advance directives

Variable	Yes (%)	No(%)
Age		
60-69	24 (63.2)	14 (36.8)
70-79	16 (80.0)	4 (20.0)
≥80	9 (75.0)	3 (25.0)
Gender		
Male	27 (69.2)	12 (30.8)
Female	22 (71.0)	9 (29.0)
Ethnicity		
Malay	19 (65.5)	10 (34.5)
Chinese	28 (73.7)	10 (26.3)
Indian	2 (33.3)	1 (66.7)
Others	0 (0.0)	0 (0.0)
Religion		
Islam	20 (66.7)	10 (33.3)
Buddhism	24 (77.4)	7 (22.6)
Hinduism	2 (66.7)	1 (33.3)
Christianity	1 (50.0)	1 (50.0)
Others	2 (50.0)	2 (50.0)
Educational Level		
No formal education	7 (53.8)	6 (46.2)
Primary education	15 (78.9)	4 (21.1)
Secondary education	21 (77.8)	6 (22.2)
Tertiary education	6 (54.5)	5 (45.5)
Total	**49 (100.0)**	**21 (100.0)**

Preferences for recording advance directives

Regarding the means of how one would like to have their advance directives recorded as in Table 4, 19 (38.8%) preferred verbal promises, 17 (34.7%) would like to appoint a decision maker, while 13 (26.5%) of the respondents opted for documentation.

Table 3. Reasons against advance directives

Reason	Frequency (%)
Leave it up to God or fate.	5 (23.8)
Leave it up to my family to decide.	6 (28.6)
Leave it up to my doctors to decide.	8 (38.1)
Others	2 (9.5)
Total	**21 (100.0)**

Table 4. Preferences for recording advance directives

Method	Frequency(%)
Documented (including voice recording) indicating medical treatment preferences.	13 (26.5)
Verbal promise indicating medical preferences.	19 (38.8)
Appointment of a substitute decision maker.	17 (34.7)
Total	**49 (100.0)**

Preferences for end-of-life treatment

Under the assumption that one is in a dire situation without any hope of recovery, a majority of respondents (51%) agreed on "comfort care with pain medication only" while only 8 (16.3%) of the respondents preferred not wanting any treatment.

Table 5. Preferences for end-of-life treatment

Method	Frequency (%)
All care possible to prolong my life	16 (32.7)
Comfort care with pain medication only	25 (51.0)
I do not want any treatment	8 (16.3)
Total	**49 (100.0)**

Table 6. Preferences for possible power of attorney to execute advance directives

Method	Frequency (%)
Spouse	11 (22.4)
Adult children	19 (38.8)
Siblings	4 (8.2)
Family member (except spouse, parents, adult children and siblings)	13 (26.5)
Close friend	0 (0.0)
Doctor or lawyer	2 (4.1)
Total	**49 (100.0)**

Preferences for power of attorney

Table 6 describes the preferences for the possible power of attorney to execute an advance

directive. Three choices were indicated by more than 20% of the respondents: "Spouse"; "Adult children"; and "Family member (except spouse, parents, adult children and siblings)."

DISCUSSION

This pilot study was the first quantitative survey in Malaysia to investigate prevalence and preference of advance directives among the elderly in nursing home and senior activity centres. The overall prevalence of those who had prior knowledge of advance directive was noted to be only 11.4% out of which none had an advance directive. When compared to another survey done in Malaysia in 2004, none of their subjects had prior knowledge regarding advance directives.[19]

By 2004, advance directives had already been implemented in 69.9% of US nursing homes and in 93.6% of residents receiving hospice.[13] While in Japan by 2006/2007, 58.4% of nursing homes started using advance directives.[4, 16] This clearly shows that Malaysia is lagging behind regarding the importance of autonomy. Not only that none of the nursing homes and senior activity centres visited in this study provided advance directives services, but they also do not even promote the awareness of it.

A minority of the participants completed tertiary education. The previous studies have demonstrated that higher levels of education are associated with more positive attitude regarding end-of-life care.[27,28] However, this study shows that a large proportion (45.6%) of those with tertiary education show no interest in having an advance directive. This could be due to a strong influence of religion on their views. Another factor that may come into play is that Asian people tend to value the opinions of their family members and that of the healthcare provider over their own opinion.[29] This was reflected in Table 3 of this study.

The findings on preferences of recording one's advance directives are similar to a study done in Korea, where a majority would like to verbally express their directives and an almost equal amount that favours the appointment of a substitute decision-maker.[29] However, the use of a written document should be suggested over oral advance directives since such verbal directives are usually forgotten or misinterpreted or may not be directly reported to the healthcare provider.[26]

Conclusion

This pilot study identified that the prevalence of advance directives in Malaysia is progressing at an extremely slow pace, but it also showed that the elderly population was receptive to the concept of advance directives. The majority still preferred the usage of verbal directives and opted for the choice of comfort care only as the item of choice in the advance directives.

Awareness of advance directives needs to be imparted at every possible opportunity. The health-care personnel at primary care centre should take up the role to initiate the discussion of advance directives with every elderly patient. The awareness shouldn't be confined to just the elderly but every age group as their level of acceptance may differ, and they may be more open to its concept. An effective public campaign should frequently be held in the community to raise public awareness with the hope of propelling advancement in this field to the next level.

The limitation of this study was that there wasn't a large enough sample size to assess whether the socio-demographic characteristics play a significant role in the decision of adopting an advance directive. It also does not represent the Malaysian citizen as a whole since the study was not broad enough to include people from both walks of life (rural and urban). A larger scale prevalence survey should be conducted to substantiate the findings.

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