The Views of Older Malaysians on Advanced Directive and Advanced Care Planning: A Qualitative Study
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Abstract

The provision of optimum care for the ageing population is dependent on the understanding of their views and values on end of life issues. A qualitative descriptive study was conducted to describe views of elderly Malaysians on Advanced Care Planning (henceforth ACP) and Advanced Directives (henceforth AD), and explore factors influencing these views. Fifteen elderly subjects with ages ranging from 65 to 83 years, representing different ethnic and religious groups in Malaysia were selected for in-depth interviews guided by a questionnaire. Five core themes were extracted from the interviews: 1) Considering the future 2) Contingency plans for future illnesses 3) Attitudes towards life prolonging treatment procedures 4) Doctor-patient relationships and 5) Influence of religion on decisions related to future illness. Despite the lack of knowledge on ACP and AD, older respondents were very receptive to their concept. Although the majority agreed on the importance of planning for future medical management and having open discussion on end of life issues with their doctor, they felt it unnecessary to make a formal written AD. Most felt that the future was best left to fate or God, and none had made any contingency plan for severe future illnesses citing religion as reason for this view. Cardiopulmonary resuscitation, mechanical ventilation and dialysis were considered by most to be invasive life prolonging treatments. We suggest that doctors initiate discussions on end of life care with every older patient and their family so as to promote awareness and introduce the concept of ACP/AD to a Malaysian setting. Asia Pac J Public Health 2007; 19(3): 58-67.

Keywords: Advanced directive, advanced care planning, elderly.

The Views of Older Malaysians on Advanced Directive and Advanced Care Planning: A Qualitative Study

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Introduction

Quality of life is an intensely personal and variable concept. Thus, in health care, health related quality of life is best assessed on the basis of the patient's experience. In keeping with a patient centered approach, frequent frank discussions with the patient about lifetime goals, values and aspirations, focusing on the patient's preferences and perception of health related quality of life will help the physician act on the patient's behalf. Issues related to the use of active life prolonging treatments in the dying or terminally ill older patients often create a dilemma for attending doctors. Since death is now more likely to occur at the end of a long life in this modern time, it is important to understand the views and values of our elderly. A step further in affirming these views and values with their doctors would be by making an advanced directive or an advanced care plan.

An advanced directive (AD) is an oral and written instruction about a person's future medical care in the event he or she becomes unable to communicate. Advanced care planning (ACP) is the process of discussing end of life care with the patient while he or she is still competent, so as to develop a valid expression of the patient's wishes regarding future medical care; particularly in the event that the person is unable to make his or her own decisions.

Since the early 1990s, advanced directives have been widely promoted and even supported by public law. In the United States, the 1991 Patient Self Determination Act required all hospitals, nursing homes, and home health agencies to inquire about advanced directives. AD now have a statutory basis in all the fifty States of the United States. Despite widespread support for the concept of advanced care planning, only 10% to 20% of patients have completed such documents. The views of the older North Americans, Japanese, Australians, Canadians and Singaporeans on this subject were well documented by various published studies. In the Japanese community study, the majority of elderly participants found it suitable to express their directives by word to family and/or physician and not by written documentation. There was no strong need for legal measures in setting up an AD. Residential home
residents in New South Wales, Australia were recorded to have very low levels of formal advanced directives (available for only 0.2%). Only 1.1% of residents had ‘no-CPR’ orders documented in the medical record, while 5.6% had a formal guardian and 2.8% had an enduring guardian. Despite widespread agreement to concept of AD/ACP, the majority of elderly Singapore respondents had not even heard of their legislation on it. The views of the six different elderly groups in Sheffield, United Kingdom recorded that they did not perceive that during dying they would be necessarily ready to adhere to an advanced statement and ‘disengage’ from their lives; finding it preferable to conceptualise advanced care planning as a process of discussion and review between clinicians, patients and families. The various factors that affect the decision making regarding advanced directives are personal values, age, stress, environment, health status, knowledge as well as concern for others. Race, religion and cultural values play an important role in attitudes towards end of life decision making.

The significance of culturally influenced values have been described in studies between African American and white patients, Chinese and non-Chinese seniors as well as between other Asian subgroups including Indian with Hindu faith. In particular, patients’ respective religious and philosophical traditions are considered to have a strong influence on their attitudes towards end of life decision making.

The aim of this study was to describe the views of older Malaysians on ACP/AD and to explore the factors which influence their views. As there were no reports found on the views of elderly Malaysians on ACP/AD in our extensive literature search using Medline databases, we hope that such data will serve not only as the base line information for further research on this subject but also to assist in implementing AD/ACP in a Malaysian setting.

Methods
A qualitative descriptive design was used to address our research questions. We invited 15 elderly Malaysians with ages ranging from 65 to 83 years to participate in this study. They were patients who attended the outpatient clinics of the University of Malaya Medical Center or were admitted to the geriatric ward from 1 September 2004 to 30 September 2004. Respondents representing the different ethnic and religious groups in Malaysia were purposely selected for in-depth interviews. Four respondents were selected from the out-patient clinics and the remaining 11 respondents were hospital in-patients admitted to the geriatric ward during the same period. Those respondents who were in-patients were interviewed one day prior to or on the day of their discharge from hospital. This ensured that they were over their acute illness and were relatively well enough to be interviewed. One of the authors of this paper acted as the sole interviewer of this study. Written consents from all respondents were obtained. Ethics approval was obtained from the medical ethics committee of the University of Malaya Medical Center (UMMC). The semi structured one-to-one interview which lasted between 30 to 45 minutes was guided by a set of questionnaires and recorded to enable data collection from each participant. These respondents were encouraged and given considerable latitude to comment on points or topics they considered relevant. Those aged less than 65 and patients with certain kinds of impairment that would affect a meaningful interview (such as severe cognitive impairment, depression, aphasia, and profound hearing impairment and language barriers) were excluded from the study. Socio-demographic variables such as age, sex, marital status, ethnicity/race, religion and degree of piety, education level, previous occupation, their main caregiver (if applicable), nature of current medical illnesses, self-rated health status and, any previous experience with hospitalisation and life extending interventions for the respondents or persons close to them (siblings, relatives, friends) were recorded.

Questionnaire
Sets of general questions designed to define the respondents’ awareness, preferences, attitudes and behaviour towards AD and ACP were used. They were also designed to elicit the individual responses in their own words and to allow free response. This guide served as a checklist during the interview and ensured that the same information was obtained from the respondents. Most of the questionnaires used in this study were developed from similar studies by Seymour et al and Carese et al.

The respondents were first asked about whether they had heard of ACP/AD. They were then informed and educated on AD/ACP/living will/durable power of attorney especially those who had no prior knowledge of AD/ACP. Those who were aware were also informed so as to reinforce their correct understanding of the subject. They were asked whether they had encountered any personal experiences of hospitalisation or had been hospitalised or of death of a family member and/or close friend in the last five years. They were then asked whether they had thought about future illnesses; whether they had discussed this with others; whether they had made any contingency plan for serious future illness and their understanding of their own medical condition including available treatment options.

The respondents were asked to indicate whether they agreed or disagreed with the statements concerning ACP/AD and whom they would choose as their surrogate decision maker. They were then asked to make treatment decisions for themselves based on four hypothetical case scenarios. The examples given were: severe dementia, terminal HIV infection, terminal cancer or long term coma or vegetative state given little or no chance of recovery. Participants
were asked to imagine themselves in such states of terminal illnesses and whether in these scenarios they would wish to have the following life prolonging procedures or treatments. These included cardiopulmonary resuscitation (CPR), mechanical ventilation, gastric tube feeding, chemotherapy, radiotherapy, dialysis, amputation, blood transfusion, antibiotic therapy and pain control. The interviewer did not proceed with further questions until he was convinced that the above scenarios had been fully understood by the respondents. Only then were they asked why they made those treatment related decisions. Furthermore, different case scenarios were presented and rotated from one patient to another so as not to affect their response.

They were also asked where they preferred to die when the time came. The final question was whether their views were determined by or related to their religious beliefs. To avoid any misunderstanding or distress; throughout each of the interviews, the interviewer repeatedly reassured them that that all the questions asked and discussions on death and illness were only hypothetical in nature and that the questions used were standardised for all the participants.

**Data Analysis**

A total of 15 respondents were interviewed for this survey. Among them, seven were ethnic Malay, five were ethnic Chinese, two were ethnic Tamil and one was Eurasian. In terms of religious affiliation, seven were of the Islamic faith, four were Christian, two were of Buddhist and Hindu faith respectively. Their ages ranged from 65 to 83 years giving a mean age of 73.6 years. Ten of the 15 respondents were female. Seven patients were widowed, seven married and one was single. Nine of the 15 respondents had received less than ten years of formal education (of these four had no formal education). The other variables are listed in table 1.

Interviews were tape recorded and conducted in English and/or local Malay language depending upon the respondent’s preference. The interviewer then listened to the interview audiotapes to write expanded summaries of each respondent’s answers to the questions asked following the interview. These summaries were put into 15 separate ASCII files, one question per file, using a word processor. Each file thus contained equivalent passages representing all the respondents’ answers to a single question, and these were marked with identification numbers and delimited with brackets. Their verbal answers in the interviews were transcribed, categorised and analysed manually to describe associations in key patterns and themes. Five core themes were extracted by the interviewer, which was agreed upon by one of the co-authors who did an independent analysis of the transcripts.

**Considering the future/Advanced Directive**

Although none of our respondents had ever heard of ACP/AD or its concept, when asked on whether they had thought about their future illness, the majority of them revealed that they had not given it any thought, and that it was best to leave their future to fate or God.

A comment made by a 74 year old Chinese woman was shared by many of the respondents; ‘No, I have never thought about it, as I cannot predict when illness will come. I do not want to think about it and I will leave it to my fate.’ A 79 year old Chinese man commented; ‘No, I have never thought about it because I will take as it comes. If it is going to happen it will happen since I have no control over my health.’

Of those who did consider the future, most had expressed fear of becoming a burden to their family. The comments of a 73 year old woman with Parkinson’s disease typified feelings of this group; ‘Yes, by looking at my dying brother I have thought about what will happen to me if illness strikes me and I become older. May be I should be sent to a nursing home when I get older so that (as) not to burden my children. Yes, I have a very supportive family and they said no way that we will let you go to nursing home. You know babies are different as they are clean but if you became older you pee here and there and (you are) dirty.’

One 83 year old Indian man of Christian faith who was suffering from hypertension and diabetes mellitus had even expressed a wish to be ‘let go’ by way of euthanasia. This was an unexpected response, as he was not asked on the topic of euthanasia. His comment was ‘Yes. One of my very close friends died in National Heart Institute a couple of months back. He was in a coma before his death. I imagined myself in his place when I paid him a visit. If I were bed bound and suffering, I’d rather take a short cut. In such conditions, family will take care of you for the first few months but after a while you became a nuisance to them. They will be doing a favour to me if they let me go. If I were to suffer I might take a lot of sleeping pills and go to sleep peacefully permanently. I believe in euthanasia.’

We talked about their understanding of their medical condition. Despite the varying levels of education amongst the group, all knew what diseases they had and they seemed to have a very positive outlook of their future. The majority of them did not seem to understand the gravity or seriousness of their illness. For instance, a fairly educated gentleman with severe chronic obstructive airway disease (COAD), who was recently admitted to the high dependency unit, stated that he was very hopeful and very optimistic of making a complete recovery. He rated himself to be in fairly good health. Another participant with prostate cancer also rated his health as good. In fact all had rated themselves as having good or fairly good health. They were of the opinion that their good health would be ensured if they adhered to their current treatment regimes and followed the advice given by their doctors.
Table 1. Demographic Characteristics of Respondents

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1 Female; M = Male
W Widowed; M = Married, S = Single
I = Indian, M = Malay, C = Chinese, O = Other
HIN = Hindu, ISL = Islam, CHR = Christian, BUD = Buddhist
HPTD = Hypertension, DM = Diabetes Mellitus, ET = Essential Thrombocytosis, COAD = Chronic Obstructive Airways Disease
must note that only one of the respondents was actually suffering from a terminal illness. At the time of interview none of them had a life threatening acute illness and had already recovered from their acute condition.

In keeping with their earlier answer, none of the respondents had made any firm decision on their future medical management should they become seriously ill. However, when the subject was brought up, half of them admitted that they would consider making such plans in advance. The others were unsure of what to do, but on direct questioning; most of them agreed that a plan for future medical management was certainly a subject they should think about or discuss with others. Three respondents felt they would make an independent decision on this matter and were skeptical of whether their family members would honour their wishes. One respondent in particular who lived alone and had three children, felt motivated to make plans in advance following the interview.

After explaining what an advanced directive meant, we asked the respondents whether they would like to make one. A third of them did not wish to make any advanced directive. This was in keeping with their decision to leave these matters to fate or God, ‘taking it as it comes’, not wanting to worry their children or leaving it up to their children to continue caring for them or otherwise. Another third felt that a verbal discussion on their future plans would suffice and did not see the need to make a formal advanced directive. The rest were very keen to make one. One eighty three year old lady stated “I think I want to do it. Because while I am gasping to death, I don’t want doctors poking me here and there, knowing that I cannot recover but because it is their duty and to please my relatives.”

Contingency plans for future illness
The respondents were presented with four hypothetical future illness scenarios namely advanced dementia, terminal cancer, coma with no or little chance of recovery and terminal HIV infection. None of the respondents had made any contingency plan for severe future illnesses in light of the given diseases. There were varied reasons given for this; “I cannot think very far away, it depends on your fate”, “what is there to plan, it is beyond my control”. Some felt it was up to their children to decide on a plan. Although some of the respondents had given it some thought, they had not made any plans. When asked, the majority of respondents agreed that their attending doctor should initiate discussions on their end of life decisions. Only three of the respondents had reservations on the matter.

The respondents were asked whom they would appoint as their surrogate decision maker should they fall seriously ill. The majority of respondents chose their family members (mainly their children) over their doctors. Two respondents preferred not to have proxy stating that they do not trust the proxy’s decision. An eighty three year old Malay Muslim lady answered that “I do not trust in proxy, they cannot represent me. They will always give permission to doctors to do their best to extend my life. Even if I choose my attending doctor as proxy, (I might not get the same doctor to represent me).”

We then asked them where they would want to receive medical care if they were dying. The majority did not have any preference, some citing fate and circumstances as the deciding factor. Interestingly, the respondents who preferred to die at home were mainly from the Malay Muslim ethnic group.

Attitudes towards life prolonging treatment procedures
The respondents were asked if they themselves, their family members or friends had been hospitalised for serious illnesses in the general ward/ICU/CCU. Four had not had any experience or witnessed this. Only three of the respondents had experienced this for themselves. The others had shared these experiences with family members and friends.

We asked the respondents to imagine themselves in four scenarios of serious illnesses namely terminal cancer, severe dementia, terminal HIV and coma where there was no or little chance of recovery. They were then asked whether they would welcome life prolonging treatments if they were in such conditions. Five respondents welcomed life prolonging treatment in light of such terminal illnesses despite there being no hope of recovery. One of them stated that she wanted to live for her children. The remaining ten respondents had refused CPR should their heart stop but were varied in opinion regarding mechanical ventilation, gastric tube feeding, dialysis, chemotherapy, radiotherapy, amputation, blood transfusions and antibiotic therapy. Among this group, the majority agreed to gastric tube feeding, chemotherapy and/or radiotherapy, amputation and to blood transfusion and antibiotic treatment. Only two patients refused any form of life prolonging treatments, even blood transfusion and antibiotics. On the question of pain relief during terminal illness, all but one agreed to receive any form of pain treatment and wanted to be kept comfortable when death is near. The one respondent who refused pain relief in our study stated “If I became ‘useless’ (powerless) due to such illnesses, pain is immaterial for (to) me.”

Doctor-patient relationship
The respondents were found to be open to the idea of direct communication with their attending doctors. When the respondents were asked if they would like to be informed of their diagnosis and prognosis if they were terminally ill, all except one respondent wished to be informed. One Malay lady who did not wish to be informed of her diagnosis stated “you can tell my relatives. I do not think Malay patients will want to know.” She was the same respondent who was very keen to make a living will when the subject was discussed. Contrary to her remark, we found that all the other Malay respondents did want to
be informed of their diagnosis and prognosis.

We asked the respondents whom they felt should inform them of their diagnosis and prognosis. All but one wanted their doctor to disclose such information. One said, "I do not mind (whether the) attending doctor or the children (tell me) as long as I come to know about it".

Responses such as "I want to be told point blank", "tell me the truth" or "tell me straight away" confirmed that the respondents wanted a direct and honest approach from the doctors on this matter. With regards to whom they should discuss advanced care planning with; the majority of respondents preferred their hospital based specialist to their regular general practitioner. From their statements, they demonstrated their confidence in hospital specialists. "They know me better", "they have more experience", "they are more appropriate to discuss this with", "they would be the ones treating me if I were seriously ill", were among the views given.

Influence of religion on decisions related to future illness

When respondents were asked about their degree of piety, most of them considered themselves to be religious. Half of the respondents admitted to being strongly religious. The others stated that they were moderately religious but only one who was of Christian faith admitted to not being religious. Respondents were then asked whether their religious belief had influenced their views with regards to future illnesses. The majority respondents believed that their views were indeed influenced by their religion. This was especially so among those of Islamic faith. In contrast, all those of Buddhist and Hindu faith believed that their views were personal views and not influenced by their religious beliefs. Three of the five Christian respondents believed that their views were influenced by their religion. These views seemed to determine their response when asked about where they wished to receive care if they were dying. Some respondents preferred to die in their own home so that they would receive the final religious rite for the dying person. Seven out of 15 had no particular preferences. Their responses were recorded as "when the time comes for me it does not matter", "leave it to fate", "beyond my control". Three respondents specifically wanted to die in hospital so as to receive medical care when they were dying.

Discussion

Living longer offers unprecedented opportunities for personally and socially fulfilling lives, but it also presents individual and societal challenges related to quality of life in old age, including autonomy, social interaction, health care and community involvement. To provide optimal care for the ageing population, advanced directives should be a routine part of standard medical care and, when possible, conducted with the proxy decision maker present. Since 1996, the Advanced Medical Directive Act was made a law in Singapore; a neighbouring country of Malaysia with similar cultural and religious values. However Low et al. observed that most elderly Singaporeans seen in their setting have not even heard of the existence of this legislation, let alone executed an advanced directive. Therefore it was not surprising to note that none of our respondents had heard of AD/ACP or its concept despite having had personal experience with hospitalisation or serious illnesses or witnessed it in their friends or loved ones. The majority of them thought issues related to future illnesses were best left to fate or God and resisted the idea of planning for the future. It was shown that the willingness to consider future illness and the end of life is not universal; patients in some communities are reluctant to consider or speak about such matters. Another study by Carrese et al showed similar themes where most participants were resistant to planning because they considered these matters to be God’s domain. God, in this view, is in control of what happens in the future and at the end of life, and it is not the individual's role to be concerned about these matters or to plan actively for them. In their study many patients articulated a preference to "cross that bridge" of making decisions about possible serious future illness only when they had to i.e. when confronting those issues in real time. This seems to be a specific application of the more general "one-day at a time" philosophy. The attitude of 'take it as it comes' was also observed among a few respondents in our study. Schiff et al found that while older people had little prior knowledge of living wills, most were able to express clear views on the type of care they would wish to receive if incapacitated in the future. Gordon and Shade in their study of 5,117 seniors showed that patients were three times more likely to establish an advanced directive if they had been asked about their wishes. In fact, one of the respondents in this study was ready to execute a living will immediately after the interview when asked about this. When specifically asked about making formal written AD, only a few agreed and the majority thought it was not necessary. Those who did agree with the idea of AD suggested that a verbal discussion would suffice. Fear of becoming a burden to their family was the common reason given by the respondents who agreed with the suggestion. On a similar note, a majority of the Japanese participants in the study by Akabayashi et al found that it was suitable to express their directives verbally to family and/or physician and not by written documentation.

Most of the respondents in this study agreed that planning for future medical management was something they should think about or discuss with others. They also agreed that their attending doctor should initiate discussion on their end of life decisions. Aitken advocated that the outpatient setting is ideal for developing an advance care plan, and the primary care
physician is well situated to initiate the discussion. However, the majority of our respondents preferred their hospital based specialist to their regular physician is well situated to initiate the discussion. This may be explained by the fact that patients usually present themselves to hospital for serious illnesses and hence would naturally be seen by a hospital specialist. Moreover the majority of respondents from this study were currently attending regular follow up visits at the out patient specialist clinic of this hospital and was being seen by either a geriatrician or family physician specialist. Therefore it was natural to have more confidence in them. Another possible explanation may be a lack of confidence in general practitioners amongst the older population due to the fact that currently there is no formal geriatric training for them in Malaysia.

The majority of respondents in this study chose their family member mainly their children as their surrogate decision maker if they had to choose one. Of all the respondents who were married only one chose their spouse. This could be because their spouses were equally frail or that they had greater confidence in their children. Three chose their doctors, not wanting to burden family members with the decision. Similarly, the study by Akabayashi et al also showed that the most suitable proxy is considered to be a family member, relative, or spouse. Even so, two of our respondents expressed some doubts that their family members may not honour their wishes in dealing with their end of life issues, one even declined to choose any surrogate decision maker citing this very reason.

Studies have confirmed earlier observations that dying people and their families experience a wide range of unmet needs, while receiving very costly care. One large U.S. study found considerable suffering and inappropriate use of resources was observed in those admitted to an academic hospital with severe medical conditions and who had a median survival of six months. Many patients died in pain or with high symptom burdens. A study by Schiff et al showed 90% to 94% of participants refused CPR and mechanical ventilation at the end stage of terminal disease. Similarly, most of the respondents in our study considered CPR, mechanical ventilation and dialysis to be aggressive and invasive procedures and therefore they did not agree with such life prolonging treatments. This observation was in concordance with other studies that have shown that most patients would refuse life prolonging treatment if these were deemed futile. Akabayashi et al observed that the majority of respondents in their study refused all life sustaining treatment and elected only to have pain relief if they were close to dying with no hope of recovery.

In contrast, Low et al showed that the majority of Singaporean Chinese nursing home residents would choose CPR, artificial ventilation and nasogastric feeding even in the face of futility. They explained that their participants' response could have been influenced by their religious values, their fear of death and dying or by their very strong will or desire to carry on living no matter what the circumstances might be. Among respondents in our study, the majority declined CPR, and mechanical ventilation, but agreed to nasogastric tube feeding. The respondents' personal experiences or their exposure to the experiences of their family members or friends may have influenced their decision making regarding such treatments. One of the respondents was even keen on euthanasia should he be terminally ill. In this study all except one wished to be pain free and comfortable if they were dying. This opinion was also noted in the study by Schiff et al where the participants preferred comfort only care nearing death.

The desire to know and to be told the diagnosis and prognosis of one's illness is the norm in the West and this becomes particularly important if one were diagnosed with a terminal condition. This was also found to be true for the majority of Japanese respondents and among older Singaporeans in the study by Akabayashi et al and Low et al respectively. Similar findings were observed in our study where all except one respondent desired to be informed of their diagnosis and prognosis by their doctor if they were terminally ill. The majority of our respondents were found to be open to the idea of direct communication with their attending doctors. The respondents wanted a direct and honest approach from the doctors on the issues related to their illness. Therefore the common belief or assumption in Asian culture that disclosure of diagnosis and prognosis to relatives is preferred instead of to patients may not be true in the Malaysian population.

It was found that race, ethnicity and cultural values play an important role in advance care planning. Malaysia has a diverse multi ethnic population consisting of Malays (50.8%), Chinese (26.3%), Indians (7.5%), the Indigenous group (12%) and others (3.5%). It was observed that religion highly correlated with ethnicity in Malaysia. Islam was the most widely professed religion with 60.4% of population. Malaysia, being a multi religious nation, also had a fair share of those embracing other religions such as Buddhism (19.2%), Christianity (9.1%), Hinduism (6.3%) and Confucianism/Taoism/other traditional Chinese religion (2.6%) as revealed in Census 2000. This study had sought to find out if there is any difference in perception among different ethnic/religious group in Malaysia. We found that the majority of respondents believed that their views were influenced by their religion. This was especially so among those of Islamic faith. The majority of respondents did not have any preference on where they died some citing fate and prevailing circumstances as the deciding factor. Interestingly, the respondents who preferred to die at home were mainly from the Malay Muslim ethnic group. The main reason given...
was so they could receive final religious rites from their family.

The number of respondents was not large enough for us to make any observations with regards to whether the variables of age, level of education or sex played a significant role in the respondents’ decision making process. Nevertheless, it was interesting to note that the two respondents who refused to designate a surrogate decision maker had received more than ten years of education. They had also refused all forms of life prolonging treatment including CPR. All five respondents who wanted CPR despite there being no hope of recovery had received less than ten years or no education. This may suggest a correlation between level of education and their decision making process. However, a larger sample of respondents would be needed to explore this further.

Conclusions

This exploratory study showed that despite a lack of knowledge on ACP/AD among older Malaysians, they were very receptive to its concept. They had a clear understanding of issues related to it once it was carefully explained. However the majority of respondents in this study was resistant to making a formal advanced directive and preferred to express their directives verbally to a family member. Thus further education of the population at large should be carried out before implementing the concept of an advance directive for older Malaysians. We suggest that it should be the duty of the attending doctors to initiate a discussion with every older patient and their family on the subject related to the end of life care so as to promote awareness. This should be carried out without being prejudicial on the outcome as there may be some who are willing to execute a living will if explained properly. Quality of care at the end of life can be achieved by a balanced understanding of patients’ religious beliefs especially among Malay Muslims, as well as the perception of the individual patient and their family members.

The study also showed the importance of establishing an honest and open communication between doctors and patients at all times. Due to religious and cultural sensitivity the respondents were not asked about issues related to euthanasia. However, one of the respondents did voluntarily talk about euthanasia. Therefore the perception of older Malaysians on euthanasia should be included in a future study. The limitation of this study was its small number of respondents whose views cannot fully represent the views of all older Malaysians. Also, most of the respondents were not terminally ill to appreciate the issues at hand. Due to the small numbers, we were unable to fully observe whether the variables of age, level of education or sex played a significant role in the respondents’ decision making process. Therefore, a larger population study is needed especially among terminally ill older Malaysians from all ethnic groups to further substantiate these observations.

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References


