

Chapter 10

End-of-Life Decision Making in Hong Kong: The Appeal of the Shared Decision Making Model

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10.1 Introduction

Making decisions about end-of-life care (EOL care) for the terminally ill is often difficult for patients, family members and health care professionals, as EOL decision-making poses legal, medical, ethical, religious and cultural issues that cannot be easily tackled, such as considerations of the patient's dignity and autonomy, and 'paternalism.' The case of the 41-year-old brain damaged woman, Terri Schiavo in the U.S. (who was in a vegetative state for more than 15 years) has provoked discussion of the right-to-live/right-to-die and the implementation of advance directives

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(including living wills, health care proxies/durable power of attorney). In particular, the case also raises a crucial question: “who should be the right person to make the decision to embrace the EOL care?”

Advance directives (ADs) have been widely recognized in some Western societies—e.g. the U.S., Canada, Australia—as instruments for competent persons to express their prior treatment choices of EOL care (for example, with respect to withdrawal/withholding life-sustaining treatment) before they become incapable of making such decisions. However, in many cases, ADs have failed to guide clinical decision-making and their utility has been questioned (Biegler et al. 2000). In addition, their application to non-Western societies has also been studied (Akabayashi et al. 2003; Bito et al. 2007; Bowman and Singer 2001; Colclough and Young 2007; Kwak and Haley 2005). According to the liberal model, the establishment of ADs is rooted in the principle of respect for autonomy. The fundamental value that underpins the use of ADs is the principle of respect for autonomy. Human beings should have the right to demand their EOL care in accordance with the advance medical instructions that they have made before they become mentally incapacitated. ADs were designed to solve the dilemma of decision-making in the case of patients who were no longer capable of exercising self-determination, and to avoid paternalistic decision-making by the physician or the family (Vollmann 2001).

Aside from giving advance treatment instructions, patients can use ADs to appoint their proxies. In the absence of ADs, the EOL decision will usually be made by the family. According to the prevailing liberal model, neither the proxy nor the family is supposed to make their *own* decision (Veatch 1998). Rather, when the patient loses his/her decisional capacity, the surrogate decision-maker (the proxy or the family) is expected to follow a substituted judgment standard by imagining being in the patient’s situation, and then figuring out what s/he would have chosen for him/her had s/he been mentally competent and fully understood his/her situation. When no definite choice could be derived from going through this thinking process, the surrogate decision-maker is expected to fall back on the principle of best interests. According to this principle, the surrogate decision-maker should follow what a reasonable person would have chosen to promote his/her best interests had s/he been in the circumstances of the patient. The family is supposed to make the decision for the patient but not for themselves. The interests of the family are marginalized. The decision of the family merely serves as a means for the patient to exercise his/her autonomy or protect his/her best interests.

Thompson et al. (2003) conducted a vignette study, using hypothetical cases, to compare the views of cancer patients, healthy controls and medical staff on the binding nature of advance directives, and whether instructions in advance directives should be followed because they are “the right thing to do,” and not because they are legally binding. Results have shown that in cases with cancer patients, instructions laid down in the ADs are considered less binding by the participants of the study than the opinions of physicians and nurses. (Thompson et al. 2003, pp. 297–298). Recently, the debates about a culture-based approach to EOL decision making have increased (Akabayashi et al. 2003; Bito et al. 2007; Bowman and Singer 2001; Colclough and Young 2007; Kwak and Haley 2005). However, it is

argued that autonomy has a transcultural value (Sanchez-Gonzalez 1997). Research findings have shown that Asians were more likely to prefer family-based decision making than other ethnic groups (Chan 2004a, b; Ohi 1998; Tuschida 1998; Tse et al. 2003; Ohara 2000).

In Hong Kong, ADs are still not commonly used in EOL care planning. In August 2006, the Law Reform Commission of Hong Kong released its report “Substitute Decision-Making and Advance Directives in Relation to Medical Treatment” (2006). The Commission recommended that the Government should play a role in promoting public awareness and understanding of the concept of ADs. Only in July 2010 did the Hospital Authority issued the first detailed guidance on ADs in adults for clinicians in Hong Kong. However, the principle of autonomy that underpins the use of ADs is rooted in the culture of Western societies, and controversies exist about its applicability to non-Western societies. Furthermore, even with an EOL decision that is made with the aid of ADs, there may still be a risk of a premature death, or a prolonged and undignified dying process with avoidable distress and suffering. This risk can be minimized if the decision is regulated and guided by a public policy framework, and guidelines are based on a plausible, ethical EOL decision-making model. Yet there is no universally accepted model across different cultures. The key issues of the controversy are concerned with the role of ADs and the problem of determining who has the principal authority to make decisions about EOL care for the terminally ill.

The study reported in this chapter aims to examine opinions on life-sustaining treatment and ADs of patients, family members, and health care providers in Hong Kong with respect to who should be the principal decision-makers for the patient in various EOL conditions, and how to resolve the conflicts among various stakeholders in the decision making process. One of the main objectives of the study is to construct an ethical model for EOL decision-making that could be practiced in the cultural context of Hong Kong, and compare it with the liberal model, which is prevalent in the US and some Western other countries.

To achieve the above aims and objectives, the study investigated the views of advanced cancer patients, family members, physicians and nurses, by questionnaire surveys and face-to-face interviews based on two vignettes, with the first one adopted from Sahn et al. (2005) study in Germany and the second from Thompson et al. (2003) study in Scotland.

10.2 Research Design, Respondents, and Methodology

There are four groups of respondents in the study: advanced cancer patients ($n=34$), family members¹ ($n=40$) and health care providers: doctors ($n=23$) and nurses ($n=42$). The respondents were recruited by the snowball method in the hospice

¹ “Family members” included 6 bereaved relatives and 34 relatives accompanied advanced cancer patients attending the outpatient clinics.

center of the Department of Clinical Oncology and the out-patient clinic of the Palliative Care Unit of two public hospitals in Hong Kong respectively. The study was conducted from November 3, 2008 to April 28, 2009.

Data was generated through a combination of quantitative and qualitative research, i.e. questionnaires and individual face-to-face interviews. The aim of the questionnaire study is to collect data about respondents' in the following four aspects:

1. Demographic data, personal attribute, and relevant background information
2. Value and attitude profiles
3. Knowledge about different aspects of end-of-life treatment and care
4. Subjective experience in regard to life sustaining treatments (LSTs) and ADs
5. Choice of EOL decision making model

Self-administrated questionnaires were provided to medical professionals beforehand. For patients and family members, their responses to the questionnaire items were codified by the interviewer. After the completion of the questionnaire, two vignettes were presented to the respondents for individual interviews. The respondents were asked to approve or disapprove of the decisions made by the doctors in the vignette. After that, they were asked to state their own preferences if they were in a similar situation. They were then asked to explain the reasons for their responses to the two vignettes.

Analyses were conducted to identify significant relationships between data collected from the questionnaire survey and respondents' judgments and preferences in response to the two vignettes. SPSS 17.0 (SPSS Inc., fall 2008) was used to process the quantitative data.

All interviews and discussions were recorded by MP3 recorders and were transcribed verbatim with the help of software Express Scribe. The thematic analysis and approach mainly followed the methods used by Ritchie and Spencer (1994). The preliminary classifications of codes were in accordance with the key issues or questions in the vignettes, as well as the categories from Thompson et al. (2003). Revision and modification of codes were carried out in the process of indexing each transcription. The findings, including translated quotations from the interviewees, were then put into charts.

10.3 Results

10.3.1 *Vignette 1*

A 58-year-old patient has survived a bowel cancer operation, but now has metastases in the liver and lungs, which are being treated (chemotherapy) and which are stable at the moment. Now she is reasonably well and cooks in the afternoons for her granddaughter.

When she has a heart attack, which results in cessation of the heartbeat, she is not resuscitated because her husband says that she did not want to be resuscitated.

	Patients	Family members	Nurses	Physicians	<i>p</i>
Right/wrong	20.8/79.2 (n=24)	32.4/67.7 (n=37)	44.7/55.3 (n=38)	70/30 (n=20)	<0.01
Interviewee's preference	16.7/66.7/16.7 (n=30)	22.5/67.5/10 (n=40)	58.5/36.6/4.9 (n=41)	78.3/13/8.7n.s. (n=23)	

Fig. 10.1 Responses to Vignette 1 in the four groups of participants: patients, family members, nurses, and physicians

	Professionals	Non-professionals	<i>p</i>
Right/wrong	53.4/46.6 (n=58)	27.9/72.1 (n=61)	<0.005
Interviewee's preference	65.6/28.1/6.3 (n=64)	20/67.1/12.9 (n=70)	<0.001

Note: The chi-square-test is used above in comparing frequency of answer in groups and association with categorical variables. The figures shown above are given in percentage. ‘Right/wrong’ indicates opinions that express agreement or disagreement with doctor’s decision mentioned in the vignette. ‘Interviewee’s preference’ indicates respondents’ own decision for the same circumstance and the three options are: not want to be resuscitated/ want to be resuscitated/ not want to make any definite statement.

Fig. 10.2 Responses to Vignette 1 in participants regrouped as professionals (nurses and physicians) and non-professionals (patients and family members)

The decision of the doctor was,

- *Right*—because the patient did not want to be resuscitated
- *Wrong*—because her quality of life was quite good and death was not near

Would you, in this situation, if you had been given an advance directive,

- not want to be resuscitated,
- want to be resuscitated,
- not want to make any definite statement. (Figs. 10.1, 10.2)

The results indicate that 20.8% of patients (*n*=24), 32.4% of family members (*n*=37), 44.7% of nurses (*n*=38), and 70.0% of physicians (*n*=20) approved the doctor’s decision in Vignette 1 (*right—because the patient did not want to be resuscitated*), while 79.2% of patients, 67.7% of family members, 55.3% of nurses, and 30.0% of physicians disapproved the doctor’s decision in Vignette 1 (*wrong—because her quality of life was quite good and death was not imminent*). When asking the respondents’ preferences in case they were in the similar condition: 16.7% of patients (*n*=30), 22.5% of family members (*n*=40), 58.5% of nurses (*n*=41), and 78.3% of physicians (*n*=23), would not want to be resuscitated; 66.7% of patients, 67.5% of family members, 36.6% of nurses, and 13.0% of physicians would want resuscitation; 16.7% of patients, 10.0% of family members, 4.9% of nurses,

and 8.7% of physicians did not want to make any definite statement. In sum, if the results were categorized as two groups: professionals (nurses and physicians) and non-professionals (patients and family members), 53.4% of *professionals* (n=58) considered that the doctor’s decision in Vignette 1 was *right*, 46.6% disapproved of the decision, while 27.9% of *non-professionals* (n=61) approved the doctor’s decision in Vignette 1, 72.1% disapproved the decision. Of professionals (n=64), 65.6% would not want to be resuscitated, 28.1% would want resuscitation, and 6.3% did not want to make any definite statement, if they were in the similar condition. For non-professionals groups (n=70), 20.0% would not want to be resuscitated, 67.1% would want resuscitation, and 12.9% did not want to make any definite statement.

The phrase “death was not near” is ambiguous. It may mean “death from cardiac arrest was not imminent” or “death from her underlying cancer was not imminent”. Follow-up interviews clarified that the latter was the understanding of the respondents who disapproved the doctor’s decision.

10.3.2 Vignette 2

A 68-year-old retired male lives with his wife and enjoys hiking. Although it was discovered that he has terminal liver cancer, his condition is stable and his life remains normal. In his advance directive, it is clearly stated that he does not want any life-sustaining treatment under a life-threatening medical situation. A few days ago, he was infected with pneumonia and was sent to a hospital. Since his life was threatened, the doctor decided to give antibiotics to the patient in order to save his life.

The decision of the doctor was,

- Right because the patient has a fair quality of life and antibiotics are not only for sustaining-life, but also effective in treating pneumonia
- Wrong because the patient’s will is being ignored

Would you, in this situation, if you had given an advance directive,

- not want to receive antibiotics
- want to receive antibiotics
- not want to make any definite statement (Figs.10.3 and 10.4).

The results of Vignette 2 indicate that 92.0% of patients (n=25), 90.6% of family members (n=32), 80.5% of nurses (n=41), and 95.2% of physicians (n=21)

	Patients	Family members	Nurses	Physicians <i>p</i>
Right/wrong	92/8 (n=25)	90.6/9.4 (n=32)	80.5/19.5 (n=41)	95.2/4.8 <i>n.s.</i> (n=21)
Interviewee’s preference	6.9/72.4/20.7 (n=29)	13.2/71.1/15.8 (n=38)	22/70.7/7.3 (n=41)	13/82.6/4.3 <i>n.s.</i> (n=23)

Fig. 10.3 Responses to Vignette 2 in the four groups of participants: patients, family members, nurses, and physicians

	Professionals	Non-professionals	<i>p</i>
Right/wrong	85.5/14.5 (n=62)	91.2/8.8 (n=57)	<i>n.s.</i>
Interviewee's preference	18.8/75/6.3 (n=64)	10.4/71.6/17.9 (n=67)	<i>n.s.</i>

Note: The chi-square-test is used above in comparing frequency of answer in groups and association with categorical variables. The figures shown above are given in percentage. 'Right/wrong' indicates opinions that express agreement or disagreement with doctor's decision mentioned in the vignette. 'Interviewee's preference' indicates respondents' own decision for the same circumstance and the three options are: not want to receive antibiotics/ want to receive antibiotics/ not want to make any definite statement.

Fig. 10.4 Responses to Vignette 2 in participants regrouped as professionals (nurses and physicians) and non-professionals (patients and family members)

approved the doctor's decision (*right—because the patient's quality of life is fair and antibiotics is an effective treatment of pneumonia*), while 8.0% of patients, 9.4% of family members, 19.5% of nurses and 4.8% of physicians disapproved (*wrong—because the patient's will is being ignored*). When asking for the respondents' preferences in case they were in a similar condition: 6.9% of patients ($n=29$), 13.2% of family members ($n=38$), 22.0% of nurses ($n=41$), and 13.0% of physicians ($n=23$) would not want to receive antibiotics; 72.4% of patients, 71.1% of family members, 70.7% of nurses, and 82.6% of physicians would want to receive it; 20.7% of patients, 15.8% of family members, 7.3% of nurses, and 4.3% of physicians did not want to make any definite statement. In sum, if the results were categorized as two groups: professionals (nurses and physicians) and non-professionals (patients and family members), 85.5% of *professionals* ($n=62$) approved of the doctor's decision, 14.5% disapproved it, while 91.2% of *non-professionals* ($n=57$) approved of the doctor's decision, and 8.8% disapproved the decision. Of professionals ($n=64$), 18.8% would not want to receive antibiotics, 75.0% would want to receive it, and 6.3% did not want to make any definite statement if they were in the similar condition. For non-professionals groups ($n=67$), 10.4% would not want to receive antibiotics, 71.6% would want to receive it, and 17.9% did not want to make any definite statement.

10.3.3 Reasons for and Against the Doctor's Decision

The responses of Vignette 1 may seem to show that non-professionals tend to disregard the wishes the patient laid down in ADs, tend to consider ADs less binding than health professionals, and lay more emphasis on the quality of life of the patient than on autonomy (Sahm et al. 2005). Yet the responses to Vignette 2 show no such difference. This result can be explained by different perceptions of treatments

mentioned in the vignettes. Although both resuscitation and antibiotics are considered as life-sustaining treatments, respondents believed that the former is more invasive than the latter. Further, some respondents regarded antibiotics as medicine for curing pneumonia rather than a kind of life-sustaining treatment that can only prolong life without improving patient's quality of life. The reasons for this response towards the doctor's decision in the vignettes therefore cannot be explained simply in terms of their attitudes towards the dilemma of autonomy vs. quality of life. Sahn et al. (2005) approach was quantitative, but ours was both quantitative and qualitative. Respondents were asked to explain the reasons for their responses towards the doctor's choice in the two vignettes. The results of our qualitative study gives a picture seemingly more complicated than Sahn et al. thought. Aside from autonomy, respondents also explained their views of the doctor's decision by making reference to best interests of the patient, the value of the family, the value of medical knowledge, and professional experience. The key issue did not seem to be simply a matter of autonomy vs. quality of life. The following is a summary of the responses.

1. *Autonomy*: Some respondents argued that out of a respect for autonomy the patient's prior instruction should be followed; while some said that not following the AD did not compromise the value of autonomy because the wishes of the patient were not so clear, and so it was not so clear that the AD was applicable, hence ignoring it was not a violation of the patient's autonomy.
2. *Best Interests*: Some respondents said that following the doctor's decision of not prolonging life was in the best interest of the patient because his health condition was regarded as poor; while some said that such a decision was wrong because the patient's quality of life was perceived to be reasonable good.
3. *The Family*: As for the value of the family, some respondents said that if the family member acknowledged that the AD should be followed, then it should be so; while some said that if following the AD would prolong the poor health condition of the patient, the family might feel upset later on, and so it should not be followed if we really respect the family.
4. *Medical Knowledge and Professional Experience*: Some said that authority of the medical doctor should be duly respected because of his/her expert knowledge, and so his decision should be taken if s/he chooses to act against the patient's oral AD, even if it was not supported by the husband in Vignette 1. Yet some other respondents said that if the doctor trusted what the husband said, the decision of following the AD should be correct because it is a professional judgment of the medical doctor.

Respondents did not have a tendency to rely on a single value, such as autonomy—as in the case of the liberal model—to justify their views. Other values were widely addressed in the justification of their responses. Furthermore, complexities and contingencies are common in EOL situations. It is often difficult to ascertain whether the patient can foresee accurately what his/her situation will be when s/he becomes incompetent, and know exactly what is his/her own prior wish, even if here is an AD. Nor is it easy to determine whether the family knows exactly what the patient wants or is entirely trustworthy. Furthermore, terms used in AD, such as LST or

“life-threatening,” are often vague. The values that respondents drew on to justify their views, including autonomy, quality of life, the family, and so on, are not well-defined in themselves either. It is not surprising that different respondents could use the same value to justify different preferences and different values to justify the same choice. The values drawn upon by respondents therefore could not serve as predictors of their preferences.

Indeed, similar findings were generated by a questionnaire survey too. The instruments developed by Schwartz (1992) were used to measure the value profile of respondents. Four value dimensions were measured by 10 value types, which were based on 57 values. (For the mean scores and the comparison of the 10 values in different groups of participants, please refer to Table A.1 and Table A.2 in the Appendix.) The comparison of the value profile and the responses to the doctor’s choice in the two vignettes shows that in Vignette 1 the respondents who agreed with doctor’s decision have a statistically higher mean score (0.708) on the value of Benevolence, than those who disagreed with doctor’s decision (0.4849) ($F(1,101)=5.979, p=0.016$). Although such a result is found, no single value is overwhelmingly decisive in predicting responses since, as stated above, respondents also consider other values, such as autonomy and best interests, in their decision-making processes. Respondents were also asked to weigh the quality of life against the sanctity (intrinsic value) of life itself. Again, no significant results were found between the weighting and respondents’ responses in the questionnaire and in the two vignettes. The same applies to demographic background. Most respondents (50.7%, $n=70$) declared no religious faith. Christianity was respondents’ most popular religion (37%, $n=51$), with 28.3% ($n=39$) of them being Protestant and 8.7% ($n=12$) Catholics. 8.7% ($n=12$) and 2.9% ($n=4$) of respondents were Buddhists and Taoists, and one of them (0.7%) was a Hindu. Even though a high proportion of respondents were Christians, none of the respondents said that people should fight death to the very end, even if the patient’s condition was terminal and incurable. Except for being a doctor or a nurse, all the above factors are not good predictors of the responses to the doctor’s choice in the two vignettes.

10.3.4 Knowledge About and Acquaintance with LST

Findings of the questionnaire survey indicate that, in the professional group (nurses and physicians), respondents who approved of the doctor’s decision in Vignette 1 possess a better understanding of LST than those who disapproved. Knowledge about LST is examined by five questions on the truthfulness of statements on LST and the respondents are asked to answer by choosing among options provided: ‘Yes,’ ‘No,’ and ‘Do not know.’ If the answer given by respondents is correct, it will be counted as ‘1’ (in numerical sense), otherwise it will be counted as ‘0,’ and then a mean score is generated: the higher the score, the better understanding of LST the respondent possesses. In a comparison of mean scores on knowledge about LST in relation to their responses given in the vignette study, a statistically

significant difference was found among respondents who held different views about the doctor's decision, $F(1, 117) = 9.283, p = 0.003$. The mean score on knowledge about LST of those who approve doctor's decision in Vignette 1 (*right—because the patient did not want to be resuscitated*) is 0.645, which is significantly higher than those who disapproved of the doctor's decision in Vignette 1 (*wrong—because her quality of life was quite good and death was not near*), whose mean score is 0.50141. By further categorizing the respondents into two groups: professionals (nurses and physicians) and non-professionals (patients and family members), and comparing their mean scores on knowledge about LST in relation to their responses given in the vignette study, a statistically significant result is found in the group of professionals. In terms of the score on knowledge of LST, the respondents who approved the doctor's decision in Vignette 1 (*right—because the patient did not want to be resuscitated*) are significantly different from those who disapproved of the doctor's decision in Vignette 1 (*wrong—because her quality of life was quite good and death was not imminent*), $F(1, 57) = 4.368, p = 0.041$. The mean LST knowledge score for respondents who approved of the doctor's decision (0.69677) is significantly higher than the score for those who disapproved of the doctor's decision (0.58519). The difference between the means is 0.11158. The effect size d is about 0.55, which indicates a strong association between variables.

Respondents were also asked to indicate their acquaintance with LST in the questionnaire survey. There were a total of 23 respondents (including 22 patients and 1 family member) who reported that they had received LST before. The following are further details about which kinds of treatment they have received: 2 patients reported that they had received *artificial nutrition and hydration*; 4 patients had received blood products; 21 respondents (20 patients and 1 family member) had received *disease specific treatments*, and 3 patients reported that they had received *antibiotics*. No respondent from the professionals group (nurses and physicians) reported experience of being treated by LST. Due to the insufficiency of respondents' having personal experience of LST, there is no significant result between the respondents' acquaintance with LST and their responses in vignette study. However, by further investigating respondents' responses given in the in-depth interview, it is shown that experience did play a role in determining some respondents' decisions. For instance, the following three bereaved family members shared their experience at the vignette study. In her answer concerning the medical decision in Vignette 1, FM38, a family member, believed that the doctor should resuscitate the patient, since curing people is his or her duty and the patient's health condition is reasonable. But she did not want resuscitation if she were the patient in the vignette. Here is her reason given: 'I do not want to (receive resuscitation) because I myself...I think of my mother, I think she suffered a lot.' Then she started to describe how her mother was being cared at home: 'I think she was in a lot of pain. Sometimes when she took painkillers, her condition might become better. When she was brought to the park, she seemed to be very happy, seemed to be...but when she was in pain, she could not sleep at night and we would not sleep either.' This created psychological pressure among the family, especially to FM38, since 'you cannot let her (the patient) know you are crying. I may have suppressed too much, I became very weak. (...) I still cannot relieve (my emotion), so I have to visit psychologist. I know I have suppressed it for many years,

trying not to be sad. However it (taking care of the family member) is really exhausting.’ As a result, she decided not to be treated if she were the patient in Vignette 1. Similarly, when asking the preference of family member FM32, if she were the patient in the condition mentioned in Vignette 2, she preferred not to have antibiotics to avoid suffering from irreversible illness or medical treatments. This response may be influenced by her personal experience in decision-making for her mother: she once requested doctors and nurses to intubate the unconscious patient in order to facilitate her urination and defecation. Although this treatment was expected to be futile, medical professionals still followed her instruction. Eventually the treatment not only failed to improve the condition, it created greater suffering for the patient. This bereaved family member thought that the decision was ‘silly,’ and that it is better not to prolong a patient’s pain and suffering by further treatment. FM33, another bereaved family member, disapproved of the decision made by the doctor in Vignette 2: ‘He (the patient in Vignette 2) is now brought to the hospital due to pneumonia. To be honest, with cancer and pneumonia...no treatment can help the patient in such situation. Yes, what you (the doctor in Vignette 2) did is just prolonging patient’s suffering.’ He continued explaining with support from personal experience: ‘It is because the patient is old ... I am not knowledgeable in medical issues. But recently I was being told by a doctor that whenever an elderly, who is a patient with cancer, is brought to the hospital and infected with pneumonia, his or her condition is very dangerous. Just like my father, (having) pneumonia, coughing with sputum, fever ... After taking an antipyretic, the fever comes down for a while, and later his temperature rises again, (...) The sputum in his windpipe is hard to remove and it makes breathing very difficult.’ Due to these reasons, he thought that the health condition of patient in Vignette 2 is not likely to be restored, and thus the doctor’s decision to treat the patient is ‘unnecessary.’

10.3.5 The Preferred Model of End-of-life Decision Making

In the survey, respondents were asked to choose between different models of EOL decision-making. The most popular choice across the four groups of respondents is the model of shared decision making—the attending healthcare team and the family jointly making the decision after taking the wishes of the patient into consideration: 39.4% of patients ($n=13$), 65.0% of family members ($n=26$), 50.0% of nurses ($n=21$), and 65.2% of physicians ($n=15$) choose this model. The liberal model (that the EOL decision should be based on the patient’s preference) was not as popular: 24.2% of patients ($n=8$), 12.5% of family members ($n=5$), 21.4% of nurses ($n=9$), and 17.4% of physicians ($n=4$) prefer this model. Even though the patients who opted for the shared decision making model amounts to 39.4%, this was their most popular choice in comparison with other models.

The results from other questions about EOL decision making show that ADs were regarded as expressions of patients’ wishes, but that they should not be the only voice that ought to be heard in the decision making process. That patients should be treated ‘in absolute accordance’ with their ADs was not a popular choice

across the four groups of respondents: only 6.7% of patients ($n=12$), 7.5% of family members ($n=3$), 42.9% of nurses ($n=18$), and 13% of physicians ($n=3$) chose it. When asking the respondents whether it is acceptable not to follow patient's AD, although the result seems to be diverse among different groups—48.5% of patients ($n=16$) and 67.5% of family members ($n=27$) thought that it is acceptable, while 47.8% of physicians ($n=11$) thought that it is unacceptable and 43.9% of nurses ($n=18$) express a 'neutral' opinion ($\chi^2: 21.9, df=6, p<0.005$)—it does not imply that ADs were regarded as unimportant in EOL decision-making. This is seen in that, in another question, respondents were asked to express their views on how much a patient should be treated in accordance with his or her AD. The majority of the three groups of respondents below preferred that patients should be treated 'as much as possible' according to their ADs: 62.5% of family members ($n=25$), 52.4% of nurses ($n=22$) and 82.6% of physicians ($n=19$), though 40% of patients ($n=12$) regarded ADs 'just as references'.

Those respondents who thought that treatments should not be implemented absolutely in accordance with ADs were asked to answer a follow-up question: who should make the medical decision for the patient if treatments need not to be provided absolutely in accordance with his or her AD? They were also asked to state the reason(s) for their answers. Most of them, 51.9% of patients ($n=14$), 69.4% of family members ($n=25$), 79.2% of nurses ($n=19$), and 80.0% of physicians ($n=16$) thought that it should be jointly decided by family and medical professionals. Here are some major reasons given by the respondents who were choosing this option: 43 respondents (including 12 patients, 23 family members, 3 nurses and 5 physicians) thought that medical professionals should take part in the decision making process because they possess relevant knowledge and/or understanding of patients' health condition, which enables them to explain to the family members. 24 respondents (including 7 patients, 10 family members, 3 nurses and 4 physicians) believed that family members understand the patient's wishes, values or condition, so their views should take into consideration. Besides, due to their close relationship with patients, 15 respondents (including 4 patients and 11 family members) asserted that family members should decide or even have the right to decide on behalf of patients.

Similarly, when asking respondents about who should represent the wishes of the patient if the instructions of the ADs are unclear, joint decision-making by the family and medical professionals was most popular among the four groups: 41.4% of patients ($n=12$), 55.0% of family members ($n=22$), 60.0% of nurses ($n=24$), and 78.3% of physicians ($n=18$) chose this model. Even though the patients who opted for the such joint decision making amounts to 35.7%, it was their most popular choice in comparison with other options. Respondents were also asked to explain their chosen options. The following were the major reasons given by respondents who favored joint-decision making by the family and medical professionals: 46 respondents (including 10 patients, 21 family members, 9 nurses and 6 physicians) thought that medical professionals should take part because they possess relevant knowledge and/or understand patients' health condition, while 27 respondents (including 6 patients, 7 family members, 9 nurses and 5 physicians) believed that

family members should interpret patient's AD because they understand the patient's wishes, values or condition; among these 15 respondents (including 4 patients and 11 family members) also thought that family members should be involved for another reason: their close relationship with the patient entitles them to make the decision. There were also 8 respondents (6 nurses and 2 physicians) who believed that the family and medical professionals should jointly interpret the patient's AD, since both parties understand what the patients' best interest is.

Respondents were also asked to express their views on the formulation of the details of the AD. Again, most of the respondents among four groups preferred joint decision-making: 35.7% of patients ($n=10$), 67.5% of family members ($n=27$), 69.0% of nurses ($n=29$) and 91.3% of physicians ($n=21$) thought that the details of AD should be formulated by the patients, the family, and the medical professional. Even though the patients who opted for the such joint decision making amounts to 35.7%, it was their most popular choice in comparison with other options.

10.3.6 The Prevalence of Familism

The findings so far show that respondents did not in general believe that EOL decision-making should be entirely dictated by the wishes of the patient as in the liberal model, though they believed that their wishes should be taken into consideration seriously. As we have discussed in this paper, the shared decision-making model was most preferred. Medical professionals were expected to play a significant role by many respondents, due to a respect for their medical knowledge and professional experience. Family members were also expected to play a key role in the decision-making process. This shows that Hong Kong's society is still under a strong influence of familism.

Owing to the close connection and caring relationships between the patient and other family members, they often have great concern for the well-being of the patient, and so can help medical professionals to ascertain his/her wishes and their best interests. Yet according to familism, the role of the family is not confined to serve this functional purpose. The EOL decision is regarded a collective decision made by the patient and other family members, and the wishes or the interests of the patient can sometimes be overridden by the family's decision. According to familism, the patient is not conceived as an independent or isolated being but rather as a self situated in a family network. The wishes of the patient should not be dictated solely by what s/he wants for himself or herself. According to the distinction between interests *in* the self (self-centered interests) and interests *of* the self (Wicclair 1999), people are often willing to sacrifice their interests in the self, such as health, material interests, or other self-centered interests, for the sake of promoting the interests of other family members, which means that interest of the self may include the interests of other family members. According to the liberal model, one may choose not to include the interests of other family members in one's interest of the self, and make it identical with one's interest in the self. On the contrary,

according to familism, the interests of other family members are inseparable from the interest of the self, and so one's interest in the self sometimes has to be sacrificed for the sake of promoting the interests of other family members.

In the follow-up interviews of the two vignettes, a majority of respondents asserted that the family should play a significant role in EOL decision-making. For Vignette 1, 12 patients, 11 family members, 25 nurses, and 17 physicians expressed such a view. The corresponding figures for Vignette 2 are: 18 patients, 28 family members, 37 nurses, and 19 physicians. In both cases, more patients assert the significant role of the family than those who deny it. Some medical professionals justified their view for some prudential reasons, such as avoiding disputes, complaints and litigations, by following the family's choice. MP65, a physician said that in Vignette 1 'if the family requests treatments (even if the patient is in a poor condition and the doctor believes that she should not receive any treatment), the attending medical professionals can still follow the family's suggestion since it can "buy more time" for communication between the family and the doctors.'

Some respondents justified the role of the family based on a concern for the well-being of the patient. They believed that the family can help medical professionals to understand the wishes of the patient and decide what is in their best interest. Seven patients, 3 family members, and 12 physicians believed that the family understands the values, feelings, and conditions of the patient, and thus can explain or provide more information about the patient's will. Three nurses (MP 34, MP46, and MP47) said, 'the family is an important source of information (for knowing more about the patient's will) because of the close family relationship.' MP 65, a physician, said that even if the patient has an AD, s/he may have changed his mind, and the family can reconfirm the validity of the AD.

Some respondents justified the involvement of the family not for instrumental reasons or for promoting the interests of the patient. They just believed that the family has a value of its own. Quite a few respondents maintained that the family's wishes should be followed insofar as it does not violate the patient's wishes, or best interests, or if the patient has not expressed his/her wish. Some respondents even held a more radical form of familism. Three family members (FM 9, FM 26 and FM37) said that 'treating a patient is not solely a medical issue but also involves other aspects, such as financial and psychological considerations for the family.' Two physicians, MP57 and MP65, and a nurse, MP41, said that medical professionals should show concern about the feelings and emotions of the family. MP41 said that the patient's refusal of treatment should be rejected if the family thinks otherwise because 'the family members may regret not saving the patient.' Three nurses, MP47, MP49, and MP53, also expressed similar views. There were also the responses that the family should be the final decision-maker, and that their decision should override the doctor's and the patient's opinion when there is no consensus. Some respondents even thought that the interest *in* the self of patient can sometimes be sacrificed, depending of the situation. MP40, a nurse, said, 'If the illness [of the patient] is treatable, medical professionals should decide. If the patient's condition is irreversible, family members should be allowed to decide for the patient, even if the treatment [decided] may cause pain and suffering to the patient.'

In sum, the findings show that a strong ethos of familism was manifested in the interviewee's responses to EOL decision-making issues discussed in the follow-up interview.

10.4 Conclusion

Hong Kong is an Asian society with a distinctive integrated culture of East and the West. The liberal model, a prevailing theoretical model in the Western literature and law, makes EOL decision-making to be exclusively dictated by the value of autonomy, though in practice the family regularly participate in shared decision making. The results of the above discussion show that though the value of autonomy is recognized in Hong Kong, it is not as highly recognized as in the liberal model, because other values are also taken seriously. On the other hand, under the influence of the Confucian ethos, health professionals are regarded as elites, and treated with deference because their knowledge and experience are highly relevant to the well-being of individuals and society. Our findings also show that knowledge about and experiences with the use of LST do play a significant role in EOL decision-making. The involvement of health professionals is therefore crucial. Confucianism also emphasizes the value of the family. Our findings show that people in Hong Kong are still under a strong influence of familism in EOL decision-making. On the contrary, according to the liberal model, it is the patient who determines the degree to which s/he wants the family and medical professionals involved. Since Hong Kong is also influenced by Western culture, the model of shared decision-making is most preferred because it is an amalgam of medical paternalism, familism and liberalism—a possible result of East meeting West.

The study shows that a certain form of pluralism prevails in Hong Kong's society. This result provides support to the conclusion that the shared decision-making model is the more suitable EOL one for Hong Kong. Our results show that people in Hong Kong tend to draw on more than one relevant value in EOL decision-making. There is a tendency to make their preferences compatible with the relevant values, and people would try to rationalize their choice by drawing on them as far as possible. As a result, their preferences cannot be explained in terms of the domination of a single value. Furthermore, due to the complexities and contingencies of EOL situations and the fact that these relevant values are not well-defined in themselves, people can interpret them in ways compatible with their preferences. So they can use the same value to justify different preferences or use different values to justify the same choice. It follows that the values that people draw upon cannot serve as predictors of their preferences. If people's preferences had generally been predicted by the single value of autonomy, the liberal model would be a better choice for Hong Kong, and the patient should be the principal EOL decision maker. However, since there is no single value to rely on in EOL decision-making, the shared decision-making model should be a more suitable model for Hong Kong. Indeed, the Hospital Authority which provides around 90% of the hospital services in Hong

Kong adopts a consensus-building approach in its two guidelines in regard to EOL decision-making (Hospital Authority 2002, 2010). According to these guidelines, the attending healthcare team should try to build up a consensus with the patient and the family in the EOL decision-making process.

Appendix

Table A.1 Means and standard deviations of the 10 values of the Schwartz Value Survey from Four Groups of Participants (Patients, Family Members, Nurses, and Physicians)

	Patients (<i>n</i> = 25)		Family members (<i>n</i> = 39)		Nurses (<i>n</i> = 32)		Physicians (<i>n</i> = 19)	
	MSD		MSD		MSD		MSD	
Achievement	-0.191	0.628	-0.165	0.702	-0.087	0.654	0.032	0.728
Hedonism	-0.173	0.861	-0.225	0.867	-0.720	0.868	-0.449	0.990
Power	-1.016	0.870	-1.186	0.732	-1.005	0.778	-1.189	1.085
Benevolence	0.405	0.292	0.576	0.482	0.534	0.406	0.838	0.532
Universalism	0.138	0.399	0.126	0.502	0.304	0.456	0.247	0.521
Conformity	0.680	0.696	0.546	0.633	0.262	0.519	0.082	0.639
Security	0.623	0.559	0.641	0.754	0.801	0.411	0.306	0.695
Tradition	0.107	0.465	-0.340	0.698	-0.293	0.482	-0.501	0.853
Self-direction	-0.040	0.441	-0.058	0.524	0.072	0.362	0.306	0.517
Stimulation	-1.932	1.499	-1.558	1.031	-1.751	0.980	-1.378	1.131

Table A.2 One-Way Analysis of Variance (ANOVA) summary table comparing four groups of participants (Patients, Family Members, Nurses, and Physicians) in the 10 values of the Schwartz Value Survey

Source	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Achievement					
Between groups	3	0.681	0.227	0.494	0.687
Within groups	111	51.028	0.460		
Total	114	51.709			
Hedonism					
Between groups	3	5.788	1.929	2.451	0.067
Within groups	111	87.361	0.787		
Total	114	93.149			
Power					
Between groups	3	0.901	0.300	0.425	0.736
Within groups	111	78.499	0.707		
Total	114	79.400			
Benevolence					
Between groups	3	2.090	0.697	3.667	0.015

Source	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Within groups	111	21.084	0.190		
Total	114	23.173			
Universalism					
Between groups	3	0.703	0.234	1.051	0.373
Within groups	111	24.751	0.223		
Total	114	25.454			
Conformity					
Between groups	3	5.288	1.763	4.594	0.005
Within groups	111	42.590	0.384		
Total	114	47.878			
Security					
Between groups	3	2.936	0.979	2.526	0.061
Within groups	111	43.004	0.384		
Total	114	45.940			
Tradition					
Between groups	3	4.759	1.586	4.003	0.010
Within groups	111	43.984	0.396		
Total	114	48.742			
Self-direction					
Between groups	3	1.909	0.636	2.949	0.036
Within groups	111	23.952	0.216		
Total	114	25.861			
Stimulation					
Between groups	3	4.036	1.345	1.015	0.389
Within groups	111	147.115	1.325		
Total	114	151.151			

A statistically significant difference was found among four groups of participants on the following values: Benevolence, $F(3,111)=3.667, p=0.015$, on Conformity, $F(3,111)=4.594, p=0.005$, on Tradition, $F(3,111)=4.003, p=0.010$, and on Self-direction, $F(3,111)=2.949, p=0.036$. For Benevolence, as shown in Table A.1., the mean score is 0.405 for Patients, 0.576 for Family Members, 0.534 for Nurses, and 0.838 for Physicians. Post hoc Tukey HSD Tests indicate that Patients and Physicians different significantly in their mean scores ($p<0.05, d=-1.05$). For Conformity, the mean score is 0.680 for Patients, 0.546 for Family Members, 0.262 for Nurses, and 0.082 for Physicians. Post hoc Tukey HSD Tests indicate that the mean score of Physicians has a different significant from that of Patients ($p<0.05, d=-1.16$) and Family Member ($p<0.05, d=-1.03$). For Tradition, the mean score is 0.107 for Patients, -0.340 for Family Members, -0.293 for Nurses, and -0.501 for Physicians. Post hoc Tukey HSD Tests indicate that the mean score of Patients has a significant difference from that of Family Members ($p<0.05, d=1.63$) and Physicians ($p<0.05, d=1.80$). For Self-direction, the mean score is -0.040 for Patients, -0.058 for Family Members, 0.072 for Nurses, and 0.306 for Physicians. Post hoc Tukey HSD Tests indicate that Family Members and Physicians different significantly in their mean scores ($p<0.05, d=-2.023$).

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