

What Patients, Families, Health Professionals and Hospital Volunteers Told Us about Advance Directives

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ABSTRACT

Objective: An advance directive (AD) is a document that allows mentally competent individuals to make healthcare decisions about their condition that they might no longer be able to make in the future. This study aimed to explore the perceptions of AD decision-making of various stakeholders in the Chinese palliative care setting. **Methods:** Patients with life-limiting diseases, family members, health professionals, and hospital volunteers were recruited in the palliative care unit of two hospitals in Hong Kong by purposive sampling on age and sex. Qualitative semi-structured individual interviews were conducted. **Results:** A total of 96 participants, including 24 participants from each group, completed the study. Most participants were willing to discuss AD but had not heard about it before the interview. Patients regarded the decisions made in the AD as a way to

reduce their future sufferings, while they also considered the welfare of their family. Family members were concerned about the psychological burden when discussing about the AD. Health professionals emphasized the logistic and process of the AD. Hospital volunteers pointed out the impact of Chinese culture on AD acceptance and the lack of AD promotion in the community. **Conclusions:** The findings of the study indicated the need for more promotion of AD in the society. It is important to consider the opinion of a patient's family during AD discussions in a Chinese culture. Health professionals may need to identify the best timing for the discussion of AD with patients and their families.

Key words: Advance care planning, advance directives, Chinese, decision-making, end-of-life care, palliative care

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Introduction

An advance directive (AD) is a document that allows mentally competent individuals to make healthcare decisions about their condition that they might no longer be able to make in the future. The passage of the Patient Self-Determination Act in the US in 1991 captured public attention regarding patients' decision-making rights.^[1] ADs have now been legally accepted in some Western countries such as the UK, Canada, and Australia.^[2-4] However, the AD completion rate remains low in many other countries.

Palliative care often adopts a collaborative approach, with the involvement of patients, family and health professionals in the decision-making of patients with life-limiting diseases, but disagreement usually arises among these "stakeholders." A multi-center survey on cancer patients, family caregivers, oncologists, and general public participants in Korea concluded that, although all parties agreed with the necessity of AD, they had different opinions about the optimal timing for its completion and the items included in the AD form.^[5] In Hong Kong, physician-initiated and shared decision-making with patients and family members on life-sustaining treatment is the most common pattern in practice.^[6] While patients, including those with cancer or dementia, are welcomed to AD,^[7-9] their decisions are easily affected by family objections.^[8] The disagreement among various stakeholders in AD decision-making warrants an in-depth discussion of the perceptions and influential factors concerning AD among various stakeholders.

Methods

We conducted qualitative interviews with 96 participants: 24 patients with life-limiting diseases, 24 family members, 24 health professionals, and 24 hospital volunteers from two regional hospitals in Hong Kong. Purposive sampling according to age and sex was used to allow a wide variety of views. Qualitative semi-structured individual interviews were conducted after a brief introduction of the AD. An inductive thematic analysis approach was used to analyze the transcripts.^[10] Table 1 summarizes the demographic characteristics of participants. Various stakeholders' perceptions affecting AD decision-making were presented one by one, as follows.

Ethical approval

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of the Chinese University of Hong Kong. Informed written consent was obtained from all participants prior to their enrollment in this study.

Results

Overall acceptance of advance directives

Although most patients, family members and volunteers had not heard about ADs before the interviews, they were not resistant to the concept. A 46-year-old male lung cancer patient expressed his views on AD: "I would accept it [AD]... yes, if there is a statutory form of AD, I will complete it [AD] first" (P6:40). A 52-year-old female, a family member of a late-stage lung cancer patient, made the following comments about AD, "[it] should have advantages because the physician is not required to resuscitate the patient and cause further suffering once he/she has signed the AD form. If patients are in worse condition after resuscitation, they still need ventilation support or other means to extend their lives... maybe for only a single week. There is no need in such cases to extend suffering over a short period, as death will occur eventually. This would cause pain if we were forced to rescue them" (F18:8). An elderly male volunteer agreed with the intentions of AD: "Actually AD is the most relevant form to meet the practical needs of patient" (V12:26).

Patients

Some patients treated the decisions made in an AD as a way to reduce their future suffering from the disease and treatment. One middle-aged female patient with late-stage breast cancer felt frustrated about suffering from pain: "You shouldn't make me feel further pain...make me feel further pain when dying. In dying, everybody would feel comfortable" (P1:30). Another middle-aged (male) patient with lung cancer said: "The most important consideration is whether it is painful. I mean whether tube feeding would cause pain, make me suffer" (P3:48). However, they preferred health professionals to start AD discussion. A 60-year-old female patient said: "Er, if a physician asks me, I will talk about this [AD] issue" (P14:46).

While considering their physical suffering, patients were worried about their own situation and their family. Some patients emphasized their responsibilities, such as taking care of their family, when thinking about possible decisions on AD. An 82-year-old male patient with lymphoma expressed his concerns, "Yes...I am afraid there will be nobody taking care of my wife" (P17:48).

Family

Family members were concerned about the psychological burden that both patients and they would bear when health professionals introduced them to AD. One elderly female family member of an end-stage breast cancer patient expressed her concerns: "So the patients sometimes would... how should I say...it means once you talk about this [AD]

Table 1: Participant characteristics (n=96)

| Participant characteristics | Mean ±SD/n (%) | | | | |
|----------------------------------|----------------|---------------------------------|-----------------|-----------------------|-------------------|
| | Total (n=96) | Healthcare professionals (n=24) | Patients (n=24) | Family members (n=24) | Volunteers (n=24) |
| Sociodemographic characteristics | | | | | |
| Gender | | | | | |
| Male | 41 (42.7) | 12 (50.0) | 15 (62.5) | 10 (41.7) | 4 (16.7) |
| Female | 55 (57.3) | 12 (50.0) | 9 (37.5) | 14 (58.3) | 20 (83.3) |
| Age (years) | | | | | |
| 18-45 | 23 (24.0) | 12 (50.0) | 2 (8.3) | 4 (16.7) | 5 (20.8) |
| 46-65 | 46 (47.9) | 10 (41.7) | 7 (29.2) | 14 (58.3) | 15 (62.5) |
| >65 | 25 (26.0) | 0 | 15 (62.5) | 6 (25.0) | 4 (16.7) |
| Refused to answer | 2 (2.1) | 2 (8.3) | 0 | 0 | 0 |
| Education level | | | | | |
| No formal education | 6 (6.3) | 0 | 5 (20.8) | 0 (0) | 1 (4.2) |
| Primary | 21 (21.9) | 0 | 13 (54.2) | 4 (16.7) | 4 (16.7) |
| Secondary | 27 (28.1) | 1 (4.2) | 2 (8.3) | 16 (66.7) | 8 (33.3) |
| Tertiary or above | 42 (43.8) | 23 (95.8) | 4 (16.7) | 4 (16.7) | 11 (45.8) |
| Marital status | | | | | |
| Married | 57 (59.4) | 12 (50.0) | 11 (45.8) | 17 (70.8) | 17 (70.8) |
| Single | 20 (20.8) | 11 (45.8) | 3 (12.5) | 2 (8.3) | 4 (16.7) |
| Divorced/separated/widowed | 18 (18.8) | 0 | 10 (41.7) | 5 (20.8) | 3 (12.5) |
| Refused to answer | 1 (1.0) | 1 (4.2) | 0 | 0 | 0 |
| Employment status | | | | | |
| Employed | 40 (41.7) | 24 (100) | 3 (12.5) | 9 (37.5) | 4 (16.7) |
| Unemployed | 10 (10.4) | 0 | 4 (16.7) | 4 (16.7) | 2 (8.3) |
| Retired | 36 (37.5) | 0 | 17 (70.8) | 8 (33.3) | 11 (45.8) |
| Housewife | 8 (8.3) | 0 | 0 | 3 (12.5) | 5 (20.8) |
| Student | 2 (2.1) | 0 | 0 | 0 | 2 (8.3) |
| Religion | | | | | |
| Buddhism | 10 (10.4) | 1 (4.2) | 1 (4.2) | 3 (12.5) | 5 (20.8) |
| Christian | 22 (22.9) | 6 (25.0) | 7 (29.2) | 4 (16.7) | 5 (20.8) |
| Catholic | 14 (14.6) | 7 (29.2) | 3 (12.5) | 2 (8.3) | 2 (8.3) |
| Taoism | 2 (2.1) | 0 | 1 (4.2) | 1 (4.2) | 0 |
| Chinese folk religion | 5 (5.2) | 0 | 3 (12.5) | 1 (4.2) | 1 (4.2) |
| No religion | 41 (42.7) | 8 (33.3) | 9 (37.5) | 13 (54.2) | 11 (45.8) |
| Refused to answer | 2 (2.1) | 2 (8.3) | 0 | 0 | 0 |
| Household income (\$) | | | | | |
| Below 9999 | 22 (22.9) | 0 | 14 (58.3) | 7 (29.2) | 1 (4.2) |
| 10,000-29,999 | 20 (20.8) | 2 (8.3) | 5 (20.8) | 7 (29.2) | 6 (25.0) |
| 30,000-59,999 | 21 (21.9) | 8 (33.3) | 2 (8.3) | 3 (12.5) | 8 (33.3) |
| Above 60,000 | 17 (17.7) | 12 (50.0) | 0 | 2 (8.3) | 3 (12.5) |
| Unknown | 14 (14.6) | 0 | 3 (12.5) | 5 (20.8) | 6 (25.0) |
| Refused to answer | 2 (2.1) | 2 (8.3) | 0 | 0 | 0 |
| Clinical characteristics | | | | | |
| Diagnosis | | | | | |
| Cancer | 16 (66.7) | | 16 (66.7) | | |
| End-stage renal failure | 3 (12.5) | | 3 (12.5) | | |
| Motor neuron disease | 2 (8.3) | | 2 (8.3) | | |
| Heart problem | 2 (8.3) | | 2 (8.3) | | |
| Diabetes | 1 (4.2) | | 1 (4.2) | | |
| Cancer stage | | | | | |
| III | 2 (12.5) | | 2 (12.5) | | |
| IV | 10 (62.5) | | 10 (62.5) | | |
| Unknown | 4 (25.0) | | 4 (25.0) | | |
| Length of illness (years) | 6.9±8.3 | | 6.9±8.3 | | |
| Self-rated health | | | | | |

Contd...

Table 1: Contd...

| Participant characteristics | Mean \pm SD/n (%) | | | | |
|-----------------------------|---------------------|---------------------------------|-----------------|-----------------------|-------------------|
| | Total (n=96) | Healthcare professionals (n=24) | Patients (n=24) | Family members (n=24) | Volunteers (n=24) |
| Good | 6 (25.0) | | 6 (25.0) | | |
| Average | 12 (50.0) | | 12 (50.0) | | |
| Bad | 4 (16.7) | | 4 (16.7) | | |
| Refused to answer | 2 (8.3) | | 2 (8.3) | | |

SD: Standard deviation

issue, they would be unhappy..., but they must face it [AD] even though they don't want to handle it [AD]" (F25:54). Another elderly female family member of a late-stage lung cancer patient associated AD with death: "Of course I felt uncomfortable once I heard of AD...why? Because once you had heard of it [AD], you had a negative feeling that the patient would pass away soon" (F14:32).

To avoid patients negative feelings about AD, some family members are willing to be a communication bridge with health professionals to introduce AD to patients. A 20-year-old female family member of a late-stage tonsil cancer patient said: "If you can talk about this [AD] with family before talking about it [AD] to the patient, I can explain the concept of AD to them" (F20:72).

Health professionals

Interviews with health professionals focused on the discussion process and execution of AD. To start an AD discussion, the importance of patients' physical capability was noted. One middle-aged female physician expressed her concern about patient's cognitive ability of when discussing AD, "It depends on how intelligent the patient is... in terms of cognitive function, because if we are talking about the decision made at a moment when the patient is not cognitively competent, it will involve lots of abstract thinking" (H23:2). Although some participants suggested defining a specific time to start the discussion, such as at admission or discharge, others thought that it was unnecessary. One young male social worker said: "Actually, there is no best timing because having a defined time does not necessarily mean that you have a smooth and comprehensive discussion" (H22:16).

Some participants thought the purpose of the AD discussion was to enhance mutual understanding among patient, family and health professionals. An experienced male physician said: "Actually signing the AD form is not the most important thing, the communication process and the mutual understanding among family members, patient and health professionals is" (H6:24).

As for the execution of AD, there is usually disagreement between the wishes of patients and the family at the moment when the patient is dying. A young male physician spoke of his experience, "Er, I think the most difficult situation

is...when the patient is in a critical condition, they cannot express their views. While we knew that they had signed an AD, the family requested life-sustaining treatment. There is a possible situation where we cannot immediately assess the views of patients, and so either the AD instructions are delayed, or life-sustaining treatment is undertaken, which makes patients suffer" (H18:16).

Hospital volunteers

While for most volunteers this was the first time they had heard about the AD concept, they were concerned about the difficulty of initiating an AD discussion, as death is a taboo in the mind of Chinese people. One young female volunteer, a full-time student, said: "I think Chinese culture plays a role [affecting the acceptance of AD] because a traditional Chinese person would avoid talking about life and death, which leads to their reluctance to discuss AD" (V8:8). Low educational levels and poor medical knowledge were mentioned as a barrier to AD discussion. An elderly male volunteer described the difficulty of the understanding AD: "Actually I have heard of AD, but I cannot understand it because it involves lots of medical terminologies. Physicians may think they have explained it very clearly, but most ordinary people will not understand" (V12:22).

Most volunteers emphasized the need to promote AD in the community. A middle-aged female volunteer, a housewife, said: "Yes...yes, it is essential to promote it [AD] through various channels to let people know they have a choice" (V19:36).

Discussion

The findings of the study show how various stakeholders perceived AD, from different angles, indicating that we need to take a multi-faceted approach to developing programs to cater to the needs of various stakeholders to increase AD completion rates.

As in previous studies,^[7-9] most participants were willing to discuss AD, but had not heard about it before the interview. This is common in Hong Kong-more than 85% of the population had never heard of the AD.^[11] To increase their awareness to increase AD completion rates,^[12] promotion of AD should be strengthened, as suggested by the volunteers in the study. A previous study on AD

promotion in the hospital showed significant improvement in the completion rate among patients.^[13] The purpose of the AD can be stressed in the promotion process, as patients who perceived AD as facilitating the decision-making process of physician and relieving family burdens were found to be more willing to complete AD.^[14]

Patients who would like to sign AD believed that it could help to relieve their suffering at the end of life.^[15] The poorer their health condition, the higher the tendency to complete AD and refuse life-sustaining treatments.^[16-18] However, volunteers noted that low educational levels and poor medical knowledge might act as a barrier to AD discussion. High health literacy facilitates the understanding and thus completion of the AD.^[19] In Hong Kong, the level of knowledge of life-sustaining treatment is generally low. A study questioning family caregivers of dementia patients found that the majority could not describe any features of cardiopulmonary resuscitation or tube feeding.^[7] More effort should clearly be put into educating patients and their families about disease treatment to increase their readiness to discuss AD, especially in regions where low literacy is common.

The findings of the study reveal the influence of Chinese culture on AD decision-making. As the concept of filial piety is important to Chinese, the family factor cannot be ignored.^[20] Some patients in the study stressed their responsibility to take care of their families. Other studies found that patients did not want to be a burden on their family.^[21] The opinion of the family has a great impact on decisions and outcomes concerned with the AD. A study on dialysis patients found that the majority had discussed their preferences with their family before completing AD.^[22] Those who did not sign an AD believed their family knew what they would want.^[22] However, the study also reported some family members might change their minds after patients had signed AD. Family disagreement with AD decisions poses a significant problem for the execution of AD. Further investigation is required to identify the best solution for this situation.

The initiation and discussion process of AD is a highly individual affair. Health professionals may assess the cognitive ability and mental status of patients to ensure they understand the purpose and content of AD, and that their decisions will not be affected by distress – thus making them ready for AD discussion. As Chinese people tend to avoid discussing death, it is preferable if the physician-initiates discussion.^[6] Studies from Western countries have also found that asking individuals to complete AD can increase the completion rate.^[15] Health professionals can help patients to recall their feelings about what they have experienced and observed during hospitalization to facilitate their decision-making. The discussion process is important

to involve patients, family and health professionals in understanding patients' views and reducing any conflict over making decisions that might hinder the execution of AD. Thorough documentation helps ensure compliance with AD decisions.^[23] Accessibility of AD in all settings, community, ambulatory, or hospital, should be ensured.^[24]

Implications for practice

- A multi-faceted approach should be taken to studying AD
- The promotion of AD helps increase awareness and completion rates. The purpose of AD can be stressed during the promotion. Education about disease treatment is also needed
- Cultural differences exist in AD decision-making. For example, it is important to consider the opinion of a Chinese patient's family during AD discussions
- The initiation and discussion process of AD is a highly individual matter. Health professionals may need to identify the best timing for the discussion of AD with patients and their families.

Acknowledgments

The findings presented in this paper form part of a larger mixed-method study developing a concept map to clarify and display the factors influencing ADs from the stakeholder's perspective.

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Conflicts of interest

There is no conflicts of interest.

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