

## Attitudes towards Advance Directive: From the Perspective of Chinese Adults in Hong Kong

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### Abstract

*Advance Directive is a statement which a person indicates when mentally competent the form of health care he/she would like to have at a future time when he/she is no longer competent. It acts to advocate and promote patient's self-determination and autonomy. AD does not have legal status in Hong Kong currently and it is still in the consultation process. Thus, it is necessary to know the attitudes of the public towards AD. Since there are limited researches and reports to reflect their attitudes, this study aimed to explore the attitudes towards AD among Chinese adults in Hong Kong. A descriptive qualitative design was adopted. Four themes emerged from the study included: (i) maintaining autonomy; (ii) unwilling of being a burden to family member; (iii) enhancing communication and (iv) worrying about the uncertainties related to AD. Understanding these attitudes helped to facilitate the process of implementing AD in Hong Kong.*

**Keywords:** Advance Directive, Attitudes, Qualitative study, Hong Kong Chinese

### 1. Introduction

In Hong Kong, the population aged 65 or above is dramatically increasing. In 2014, the elderly have made up 14% of the whole population. It is predicted this percentage will be increased to 30% in 2039. (Census and Statistics Department, 2014). Advance directive (AD) becomes one of the major concerns for the aging population in Hong Kong.

Advance directive (AD) is written document that allow individuals to specify their medical care preferences and/or to appoint a surrogate decision maker legally. As stated by the Law Reform Commission of Hong Kong (HKLRC) (2006), AD is a statement, usually writing, in which a person indicates when mentally competent the form of health care he/she would like to have at a future time when he is no longer competent.

AD acts as a mean to understand patients' wills and values, it can also promote patient's autonomy thus patient-centered care can be provided. AD has been implemented in countries such as Australia, Canada, United Kingdom and United States. In Hong Kong, there was lack of information regarding the attitude towards AD from the public, thus, whether AD should have a legal status is still in the consultation process. This study aimed to explore the attitude towards AD among Chinese adults in Hong Kong.

### 2. Methodology

Descriptive qualitative design was adopted in this study. A convenience sample of twelve Chinese adults in Hong Kong was recruited to participate in the interview. An in-depth, open-ended, semi-structured interview was conducted. The interviews were audio-tape recorded then were being content analyzed.

### 3. Findings and Discussions

Four themes were generated in this study. They were (i) maintaining autonomy; (ii) unwilling of being a burden to family members ; (iii) enhancing communication and (iv) worrying about the uncertainties related to AD .

### 3.1 Maintaining Autonomy

Some participants had positive attitudes towards AD. They agreed that AD allowed them to make their own medical decisions especially in end-of-life treatment, and their decisions would be recorded. Thus, the end-of-life decision would be no longer depended on physicians or their family members. Moreover, they believed that their wills in the medical decision would be respected and thus autonomy could be maintained.

'To some extent, I have made my decision.... the doctors cannot prescribe any medication that they want, especially the very expensive medication.' (Ms L)

'I can tell my family about my decision if I have signed the AD and I will tell them to respect my will.' (Mr. W)

'I have no control of my own birth, I think I should have control of how I die...' (Mr. B)

Participants thought AD could give them autonomy in end-of-life decision making. It is supported by the literature that over 60% of the participants agreed that it is better to express their wishes regarding advance directives (Miyata, 2006). Having autonomy is the most frequent rationale in favor of AD. Moreover, AD acted as a mean to ensure that the autonomy will be honored in the event of mental deterioration (Crisp, 2007).

### 3.2 Unwilling of Being a Burden to Family Members

According to Xu (2004), family played an important role in making the medical decision in Chinese culture, participants had positive attitudes towards AD as it would help to decrease the sense of being a burden to family members. Throughout the interviews, participants expressed frequently the concern of family members when having critical illness. Having critical illness was regarded as the disturbance of others' lives, creating both physical and psychological burdens to family member. For example, for those who were severely ill, family member would need to go to hospital, spend time and effort in taking care of them after work. Besides, it would be unpleasant for family members when seeing their loved one lying on the bed with all sorts of tubing inserted.

'My family members have to find time to go to the hospital to take care of me. I don't want to waste their time. It is a burden to them physically and psychologically.' (Mr. A)

'When you go to the hospital and see someone seriously ill, with tubing all over him, you would feel very sorry for him...If I were him, I would rather die sooner...' (Mr. K)

'I think AD is good. I would choose to use it and discuss it with my family...if I am very sick, I don't want to live for that long...it has no point to prolong the suffering...' (Mr. Z)

'If I have made decision about what I want to do, it would help them to feel less worried.' (Ms M)

'If I have already made my decisions, my family could make decisions more easily.' (Ms H)

'If I have made the decision in advance, I can reduce their burden since they don't have to worry about whether they can make the right decision for me.' (Mr. T)

Without advance directive, family members would have to make a difficult decision when participants are critically ill. It might create conflict and frustration among family members. A research stated that AD could prevent the family members from disagreeing with their decision of their end of life treatment because it could ensure their family members understand their treatment wishes clearly (Douglas & Brown, 2002). Another research stated that some caregivers had difficulty in making the appropriate end-of-life decision for their family members since they had not communicated in advance to learn about their wishes. AD could help family member to learn about their wishes to minimize their conflict (Kwan & Salmon, 2007). Thus, in this study, participants had a positive attitude towards AD.

### 3.3 Enhancing Communication

To some participants, AD provided a chance for them to discuss their wills or end-of-life issues with family members or their loved one. It is not important if their wills were not being respected, they treasured the chance of communicating this issue with others, especially with their family members.

'For me, it is a chance to communicate this issue with my family.' (Ms H)

'AD is a mean to enhance communication among family members.' (Mr. Z)

Many people agreed that the discussion on end-of-life issue is difficult to initiate, but AD helped to initiate the conversation on it (Thompson, Barbour & Schwartz, 2003). It was further supported by Jackson et al. (2009) who stated that for patients who do not have AD, less than half of them reported that they had talked, even informally, with someone about their wishes. It was obvious that AD could enhance communication.

### **3.4 Worrying about the Uncertainties Related to AD**

Although the majority of participants had positive attitudes towards AD, some reported the worries of the implantation of AD and they were unwilling to use it. The uncertainties that the participants had encountered lead to the negative attitudes towards AD.

‘Since I am not sure about the details of AD, I don’t know when they should stop giving me treatment or how I should be treated, so how can I make the decisions?...I am not professional in medical treatment, I can only make an AD according to my personal feelings or experience. I am not sure if I can make an appropriate AD.’ (Mr. J)

‘I am afraid that I may make a wrong decision, I don’t know whether I can change it (AD) or not once I had completed it...’ (Mr. R)

‘When I have made the decision under the current situation, I am not sure whether AD is still applicable in future.’ (Mr. C)

‘Medical technology is advancing quickly. There might be a new treatment in future. If I have made my decision now, I may not be able to try the new treatment in future.’ (Mr. J) The finding in the session was consistent with the finding of other literatures. Participants who showed negative attitudes towards AD due to insufficient information received. Moreover, there was a lot of terminology in the document of AD which could not be easily understood by the public and thus lead to misconception or misinterpretation of AD (Salmond & David, 2005). It was also revealed that technological development brought the feeling of insecurity to people who have completed AD (Tarzian, Neal & O’Neil, 2005).

### **4. Conclusion**

AD could maintain one’s autonomy and prevent unnecessary conflicts from happening among family members. It could also enhance the communication with others, especially family members. Thus, most of the participants had positive attitudes towards AD. However, some showed the negative attitudes towards AD because of the uncertainties that they had encountered. In order to facilitate the process of implementing AD in Hong Kong, more information should be provided to public.

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