ATTITUDES OF CHINESE ELDERS TOWARDS ADVANCE PLANNING ON END-OF-LIFE ISSUES: A QUALITATIVE STUDY IN A NURSING HOME IN HONG KONG

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Summary

A qualitative study employing semi-structured interview was conducted to explore the nursing home elderly residents' attitudes towards advance planning on end-of-life (EOL) events. Among the eight elderly interviewed, 6 elderly declined cardio-pulmonary resuscitation (CPR) while two preferred the attempt on CPR. None of the elderly expressed fear or worry on discussing EOL issues or on decision-making. They preferred their physicians to discuss with them on the advance planning. Should they become unconscious, many of them prefer the doctor to make the decision on their behalf on life sustaining treatment. This study may pave the road for further exploration on EOL issues on the elderly population.

Keywords: *Advanced Directive, End-of-Life issue, Cardio-pulmonary Resuscitation*

Background

Hong Kong, like other developed countries, is facing a growing ageing population. In 2001 there were around 750,000 people aged above 65, accounting for 11.1% of the whole population in Hong Kong[1]. The proportion of those aged 65 and over is projected to rise markedly, from 11% in 2001 to 24% in 2031[2]. Hong Kong's elders also enjoy one of the longest life expectancy at birth in the world, being 86 years for women and 78 years for men. With advancing technology, treatment exist that could prolong life for the elderly person in a critical stage, which may not necessarily enhance the well being of the elderly. The choice of treatment and the extend of care such as cardio-pulmonary resuscitation (CPR), artificial nutritional support, the use of antibiotics would have to be considered by the patients themselves or, more commonly, by the family members who act as the patients' surrogates. These decisions at the end-of-life often involve complex decision-making. They are important final decisions for patients, families, and staff. Planning in advance is therefore widely encouraged as a way to improve quality of care at the final stage of life[3]. "Advance Planning" is the process of reflection, discussion, and communication of treatment preferences for end-of-life that precedes and may lead to an advance directive.

The concept of Advance Directives was introduced in the United States and in the United Kingdom[4-5]. This advance planning procedure is not a common practice in Hong Kong. Very often the life-sustaining decision has to be made during a hospitalisation of a severely ill elderly patient, or at the moment of crisis. The recently published "Hospital Authority Guideline on Life-sustaining Treatment in the Terminally Ill" (Hong Kong Hospital Authority Guidelines) aims at providing as an aid to the clinician to the process of decision-making where an ethically sound decision is arrived with the conjunction with the patient and/or family. Despite the intended benefit, the long introduction of advance directive, and the federal Patient Self-Determination Act requiring that hospitals routinely notify all newly admitted patients about the directive, most patients in US never actually complete the forms[6,7]. There are barriers to preparing advance directives[8]. Moreover, there is lack of discussion on end-of-life issues among elderly nursing home residents and the scope of discussion is narrow[9,10]. In a recent study it was found that the Western elderly people were resistant to planning in advance for end-of-life care[11].

In Hong Kong, the issues on End-of-Life care decision have not been widely explored, despite the Report of the Working Group on Care for the Elderly released in August 1994 affirming "Continuum of

Care"[12] and the introduction of HA guideline on life sustaining treatment. In addition, the attitudes of Chinese elders, who are the focus of care, towards the advance planning have not yet been adequately explored. Very often "death and dying" issues are thought to be a taboo in Chinese culture and it may be considered to be too sensitive to discuss with the Chinese elders. Among the few studies, Hui et al has found that 74% old age home residents desired CPR. Advanced age, not having a spouse, and female sex were independent predictors of declining CPR. If they were to become mentally incompetent, most subjects wanted the physicians or relatives to make the decision regarding the resuscitation status[13]. In another recently published local study, general household's attitudes towards death were explored. Among the 613 respondents, more of them said they could face death with ease than with difficulty[14]. In a study conducted on 237 community sample of Hong Kong elderly Wu et al noted that the Chinese participants seldom discuss death. It was also shown that one third of the sample felt uncomfortable when other people talked about death[15]. Clearly there is a need to explore the elder's wish on end-of-life issues[4,7,13,16]. A deeper understanding from their own perspectives would certainly improve the provision of personal care, which is the essence of holistic care provision. Moreover, improved communication between physicians and elderly patients is desirable[13,17-19]. To achieve these goals, physician-directed intervention has shown to be welcomed by elderly persons who would like to discuss death and planning for end-of-life treatment with a caring and knowledgeable clinician[8,17].

To explore the attitudes of Chinese elders on advance planning it would be appropriate to employ a qualitative approach. It gives the patient's perspective and the goal is to obtain information by talking to and/or observing subjects who have experienced firsthand the phenomena under scrutiny. It attempts to gain a complete and holistic view of what is being measured by using a wide array of data including documents, records, photographs, observations, interviews, case histories, and even quantitative data[20]. In the following study the physician who has been caring for the nursing home residents over several years conducted a qualitative study using semi-structured questions to explore the attitudes of Chinese nursing home residents on advance planning. An attempt is made to explore if there is really a taboo in asking the residents on end-of-life issues. This is important as much end-of-life care provision may be hindered when care operators are reluctant to cross this culturally perceived barrier towards the last phase in elderly care[21].

Methods

A qualitative study is carried out to explore the attitudes of Hong Kong nursing home residents towards advance planning. The descriptive approach to qualitative study is adopted as this is useful in utilising the principles of qualitative research design to explore situations but do not identify a clear theoretical focus[22]. It is the "tell it how it is" that the researcher tries to explore from the elderly residents. The following research questions formed the analytical core of the study:

- The subjective preference for CPR and their reasons for their choices.
- Attitudes (e.g. Fear, relief) on discussing CPR issues
- The persons whom the elders prefer to discuss advance planning
- Advocating the person to make decision on CPR if the resident becomes unconscious

Setting and subjects

Permission was obtained from a 270-bed sub-vented nursing home. Research permission was also obtained from the Ethics Committee for Research Study of the organisation running the home before the study was carried out. Most of the elderly residents require frequent attention in managing the basic activities of daily living. They were of multiple medical pathology that requires regular medical follow-up. Most of the residents are cognitive impaired and the prevalence of the condition is on the increase. Most residents require aids or helpers for mobility though around 40% of the residents are bed/chair bound.

Sampling

Participants are identified through purposive sampling. This was used to ensure that the participants have some knowledge or experience in the topics being discussed. Exclusion criteria included factors that would preclude a meaningful interview (such as cognitive impairment, aphasia, profound learning impairment, language barriers), participation in pilot interview, and those with physical or psychological impairment that do not permit a 30-minute interview. Eleven residents were approached and eight of them agree to take part in the research. The eight participants include four males and four females and their age ranges from 71 to 89 with mean age of 82. The demographic

Table 1 Demographic details of the eight participants

	Sex/Age	Marital status	Previous occupation	Major diagnosis	Mobility	Barthel Index	Wish on CPR
Case 1	M / 87	Widower	Workman	Ca Anus,CVA,IHD,HT	Wheel chair	7/20	Decline
Case 2	M / 73	Single	Chef	Ankylosing spondylitis, Bilateral fracture hips	Walking with frame	14/20	Accept
Case 3	F / 87	Widow	House-Maid	CVA, Fracture hip	Walking with frame	15/20	Decline
Case 4	M / 84	Widower	Businessman	Cervical spondylosis, paraplegia, colonic volvulus	Wheel chair	9/20	Accept
Case 5	M / 71	Widower	Fisherman /hawker	Intracerebral haemorrhage, Hypertension	Wheel chair	12/20	Decline
Case 6	F / 89	Widow	Farmer	Retinal haemorrhage, Hypertension	Walking with stick	17/20	Decline
Case 7	F / 81	Widow	Housewife	DM,CRF,IHD,SSS	Wheel chair	10/20	Decline
Case 8	F / 87	Widow	Workman	IHD, CCF, Renal impairment, pleural effusion	Wheel chair	4/20	Decline

details of these eight residents are shown in Table 1. The participants were fully informed of the purpose of the study and informed consents were signed.

Data collection and analysis

With the permission of the participants, audiotaped (using digital recorder) semi-structured interviews lasting around 30 minutes were conducted. The interviews (in Chinese) were transcribed into both Chinese and English versions. These were independently verified by local Geriatricians. The thoughts and attitudes expressed by the elderly are classified from the English transcription. The concepts and categories are marked for content analysis.

Results and discussion

The core focus of these interviews was to elicit and understand participant's views about the choice on CPR and their reasons behind. The attitudes (eg fear, relief, etc) on discussing end-of-life issues were explored. The preferred persons to discuss on end-of-life issues were also investigated. Finally the responders were asked to advocate the person to make the decision on CPR should the responders became unconscious. These five themes were considered from the interviews to be most closely tied to this core focus.

1) Wish on CPR

In this eight samples study six elderly nursing home residents declined CPR. Though contrasting with Hui's study which gave a 74% elderly old age home resident desiring for CPR 13, the findings support Hui's study in which advanced age and without a spouse are independently factors associated with the tendency in declining CPR. Other possible reason for the high CPR refusal rate is that these nursing home residents have seen or heard of the resuscitation process before. This may have provided them a more realistic view on the low success rate of such procedure, influencing their decision on declining CPR[10,13].

It was interesting to note that some of the residents may swiftly give their choice on CPR preference. A few of them discussed the matter in more details and gave their rational decision. This showed that the issue has been well thought of by the elderly in the past despite the fact that they said no one has discussed the issue with them before. This raised an important concern in the care of elderly that the domain on death and dying, though important and clearly occupied their thoughts, has not been properly addressed. It is likely that a great deal of psychological and educational input have to be given to the care providers and care staff before the end-of-life issues are properly discussed with our elderly in a sensitive and caring fashion.

2) Reasons for their wish on CPR

In this qualitative study, it was found that the reasons for declining CPR are: avoiding suffering,

a good age with contented life, not wanting the young generation having more troubles, bad experience of having (naso-gastric) tube insertion, and accepting fate. On the other hand, the reason for accepting CPR is mainly of giving it a try if it works. The responders gave reasonable view in that they would not want resuscitation should the treatment is futile. This idea agrees with the recently published HA guideline on life sustaining treatment stating that futile treatment can be withdrawn or withhold.

3) Attitudes (emotions) on discussing end-of-life issues

It is a common belief that talking about death is a taboo among Chinese elderly. Wu et al found that Chinese elderly people generally reported a low level of anxiety toward death and very few of them admitted to being extremely fear of dying 15. During the lengthy interviews in this study and the following weeks after, it appeared that these eight participants showed no worry or fear on discussing the topics on death and life sustaining issues. They instead voiced their good acceptance on talking on these subjects. "Having grown up children or children who are treating them well, or having no children at all, having plans on death and funeral arrangement, achieving a good age" are their answers to having no worry on end-of-life issues discussion. It is worth pointing out that all eight participants were happy to give their views without taking it as a taboo as many would have thought. One of the elderly actually expressed that the discussion with the doctor relieved her burden. This may indicate that further research and service on these fields is possible and worthwhile. Above all, death and dying is an inevitable fact that every one of us has to face. A better understanding on the subject would mean a more truly holistic care to be provided to the elderly population.

4) Preferred person to discuss on life sustaining issues

In discussing advance planning this study echo the view that doctor is the desired person to discuss on this matter[17,18]. The responders viewed the doctors are knowledgeable and trustworthy, while nurses may only give fractions of answers. Perhaps this study is a physician-directed interview, the responders may give a biased view that doctor is the desired person to talk to, leading to the finding that no elderly residents would see family or friends the preferred person to discuss on this topics.

5) Preferred person to decide on CPR issues when residents become unconscious

Some residents preferred the doctor to make the decision on CPR if they become unconscious. They view that doctors would be better qualified than others and that the doctors will make the right judgment. Some specifically stated that they do not want their family to make the decision as they feel the family may not take the responsibility or that the family may want an unnecessary prolongation of life. On the contrary, one resident preferred the children to make the final decision after discussion with the doctor. Some residents feel it does not matter, as they would not be conscious then. It is apparent that there are diversity in the choice of person in this scenario and one resident rightly pointed out that "***...The problem is there may be instances that there are division of opinion.... At that time there will be difficulty in communication.....***" As one can appreciate the complexity in the decision making in such circumstances, the HA guideline on this situation stated that "the decision should be a team decision led by the doctor in charge with appropriate knowledge and experience in the illness, taking into account of the views of the family..... The decision should be based on the best interest of the patient." The Guideline seems to adopt a "harmonious" stand with a more family-orientated approach that may be suitable in a Chinese culture background. However, the findings in this study showed that some of the wishes of the elderly may not be followed as they prefer only doctors but not their families to make such decision. This problem highlights the importance of autonomy of the elderly in decision making on life sustaining issues. However, when the researcher asked our residents to rate the importance of autonomy in elderly in such decision making, only few of them responded "***It is better to tell it in advance by yourself. To make my own decision." "This is my own body. Other cannot force me. This is to take away my life***".

"***His own free will***". Most other residents simply did not know what autonomy means, or the implication it entails. They responded only with stating their choice on resuscitation. It probably takes some time and educational effort to raise the understanding among the elderly population on the promotion of the right in expressing their own will.

During the interviews on death and dying issues, many residents voiced their feeling on the subject as well as mentioning a lot of other past experiences in their lives. They talked about previous financial interaction, their lives during the

Japanese war, or even "after-death-experience". The discussion likely provoked some kind of reminiscence that, although deviating from the researcher's primary objectives, enhanced a deeper understanding with the elderly. This helped the care staff gain a more comprehensive understanding to the residents.

Providing quality end-of-life care to residents is of paramount importance in delivering a holistic care to the nursing home residents. There are obstacles to provide such care in a long-term care facility [23]. There is also staff cost in burnout and fatigue[24]. To overcome these challenges administrative policy addressing staff and residents needs is helpful. Development of CPR policy [25] and education with support to staff members are essential [26,27]. Nonetheless, effective and sensitive communication between staff and residents is the first step in ensuring success in proceeding to good end-of-life care to the residents. It is hoped that the findings in this research would provide some stimulation to the care providers in the long-term-care facilities so that the elder's attitudes towards advance planning can further be explored.

Limitation of the study

The small sample size in this study means that the observation cannot be generalised to the 270-bed nursing home population, nor can it reflect the attitudes on the general elderly population in Hong Kong. Indeed, the residential home where the research took place was the first local nursing home that provides end-of-life care to the residents 28. The residents were likely to have increased exposure in encountering someone close-by passing away. There would have been more opportunities in discussing or thinking on the dying issues. The residents may therefore have given a more articulated thought during the interviews and the discussions may raise little, if any, anxiety. This limitation on the background of the residential institution does not reduce the validity of the residents' response. Rather, it demonstrates that good communication between staff and residents would enhance the residents' preparation for their last stage of life with positive and rational attitudes.

Conclusion

This qualitative study showed that Hong Kong nursing home elderly residents were able to express their cardiopulmonary resuscitation preference with their own rational grounds. The main reasons for declining CPR were avoiding suffering, satisfying with a good age, avoiding giving troubles to children, and accepting fate. The grounds for those responders who accepted CPR was that they like to give it a try if it worked. They expressed they do not desire the procedure if the treatment was futile. The discussion on advance planning and death provoked neither worry nor fear among any of the participants. Indeed some of the residents welcomed the discussion on the subjects and it was expressed as relieving the burden. Many of them preferred the doctor to discuss these issues with them, as the doctor was perceived to be knowledgeable and trustworthy. If they became unconscious many residents preferred doctors to make the decision on resuscitation while some prefered the children to be the final decision-maker after consultation with the responsible physician. Further exploration into elders' attitude on end-of-life issues is worthwhile in gaining a more comprehensive understanding to our elderly population. This would in turn help to provide a holistic care that our older persons deserve.

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