



## Original Article

## Development of an advance care planning booklet in Taiwan



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## ABSTRACT

**Objectives:** Advance care planning (ACP) is the process of discussing the wishes of people regarding end-of-life care and other related medical decisions. The aims of this study were to develop an ACP booklet in Taiwan and to identify relevant ACP issues.

**Materials and methods:** A three-stage research design was used. First, potential items were collected from the literature and were modified based on clinical situations and Taiwanese culture. Next, experts in palliative care evaluated the content validity of the items. Finally, healthy participants reviewed the ACP booklet and then discussed their experiences in focus groups.

**Results:** The significant issues identified discussing ACP included life story, current health status and habits, life-threatening conditions and suffering, medical decisions about the end-of-life care, and a number of other items. The provision of comprehensive information about the pros and cons of specific medical procedures and of palliative care was identified as important.

**Conclusion:** An ACP booklet facilitates discussion and decision-making related to end-of-life care. Furthermore, the present findings indicated that, when carrying out an ACP discussion, not only are the preferences and values of people important, but also factors related to their culture.

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## 1. Introduction

Advance care planning (ACP) is the process whereby there is discussion between individuals and their physicians, family, and friends about their preferences and wishes for future care at a time when they may lack the capacity to express such wishes [1,2]. The philosophical foundation of ACP is autonomy and that the right of self-determination should be respected and protected even if the individual cannot speak for himself/herself [3]. Traditionally, the goal of ACP is to complete a legal form through advance directive.

However, ACP now also addresses discussions with the physicians and family in order to prepare for any future medical crises [4].

Many countries have clear laws about decision-making at the end of life [5], such as the Patient Self-Determination Act in the United States and the Mental Capacity Act in the United Kingdom. In Taiwan, the Hospice-Palliative Care Act indicates that an individual can sign their will of consent to refuse life-sustaining treatment and make a choice to instigate palliative care for terminal disease [6]. The Taiwanese government has tried to disseminate information on the concepts of ACP, not only in hospitals, but also in communities, in order to promote ACP discussions and decision-making.

An ACP discussion should ensure that patients make their own end-of-life care decisions and communicate these to their family and physician(s). A large sample survey ( $n = 3476$ ) has revealed that patients with advance directives tended to choose palliative care and limited treatment compared with those without advance

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directives. In addition, the care they received was found to be consistent with their preferences [7]. Furthermore, they were more likely to die at home rather than in a hospital [8,9]. Teno and colleagues [9] conducted telephone interviews with bereaved family members ( $n = 1587$ ) and reported that 70.8% of the deceased patients had advance directives. Patients with advance directives tended to choose palliative care and were less concerned with physician communication than were those without advance directives [9]. However, people have difficulties related to discussing death and dying, and are worried about the links between ACP and euthanasia as well as the future applicability of their decisions [10].

Emanuel and colleagues [11] surveyed 405 outpatients in a clinic and 102 members of the general public, and the percentages of those who wanted to have an ACP discussion were 93% and 89%, respectively. An interview study conducted in 2012 with elderly individuals with disability showed that 75% of them would like to discuss their prognosis and future care plan if their estimated life expectation was less than 1 year [12]. Similarly, a Taiwanese study showed that more than 90% of the medical volunteers would like to participate in an ACP discussion [13]. However, the rates of completion of advance directives remains low in some countries [14,15], including Taiwan [16]. On reviewing the medical charts of patients who died of cancer in a teaching hospital in Taiwan ( $n = 829$ ), it was revealed that 99.76% of the patients had do not resuscitate (DNR) orders, but only 22.56% of these had been signed off by the patient [17]. Glick and colleagues [18] reviewed 15 studies and identified the following barriers to implementing patients' preferences: (1) a lack of education about or knowledge of ACP; (2) discordance between the patient, family, and healthcare staff; and (3) difficulties with paperwork completion. In Taiwanese culture, knowledge of ACP, attitude toward ACP, and family members' opinions are important parts of ACP discussions and decisions [19].

Various interventions have been implemented in order to increase the rate of completion of advance directives, such as the provision of written material, discussions with specialists, and educational programs for patients and healthcare professionals [20]. A review of nine randomized control trials revealed that patient-directed educational interventions improved their completion rate significantly [21]. Furthermore, Ramsaroop et al [22] reviewed 15 comparative studies and revealed a moderate effect of such interventions on the completion of advance directives [22]. Print, video, and online materials have been found to have a positive effect on knowledge and awareness of treatment choices, as well as on ACP discussions [23,24]. However, simple education without person-to-person interaction does not seem to increase the rate of completions [25,26]. Indeed, the most successful intervention was a combination of written material and repeated discussions with healthcare professionals [20,22,27]. In addition, it was found that family members were, in many cases, considered to act as surrogates, and their opinions were considered important to the decision-making [28].

Culture shapes the way people deal with illness, suffering, and death, as well as the communications and decisions related to ACP [29]. In Taiwan, the family strongly influences terminal medical decision-making, and most DNR orders are signed by family members [30]. The most common ethical dilemmas in palliative care in Taiwan are the place of care (at home or hospital), revealing the truth, hydration and nutrition, and therapeutic strategies [31]. If people express their wishes and make decisions early, they can receive the end-of-life care that they wish, and this will reduce the stress on their family members. Appropriate ACP educational material can facilitate people to think about end-of-life issues and allow them to discuss with their family. However, most material of this type has been developed in the Western societies [32].

Recently, the goals of ACP have changed from completing an advance directive to a discussion of ACP with physicians and the family [33]. ACP provides an opportunity for people to think about the value of their lives, their preferences, and their wishes, in terms of their end-of-life care, and to begin to continuously discuss these factors with their loved ones and physicians. It is therefore necessary to develop effective educational material, including information about terminal conditions and medical treatment procedures, which will help guide the discussions between patients, families, and physicians [34]. Therefore, this study aimed to develop an ACP booklet and to identify ACP issues that are significant in Taiwan.

## 2. Material and methods

### 2.1. Design

A three-stage research design was used, which included (1) collection and modification of items, (2) expert evaluation, and (3) focus groups. Prior to the commencement of the study, ethical approval was obtained from the institutional review board (IRB099-77).

#### Stage 1: collection and modification of items

The research team formulated the initial version based on the previous educational material, including *Your Life Your Choices* [35], *Five Wishes* [36], *Let Me Decide* [37]; a previous study of the Chinese frail elderly [38]; and our clinical experience when talking about ACP issues. The team had more than 10 years of experience in palliative care, and included senior nurses (SCW, CJC, SCC, HCS), a physician (YWW), and a clinical psychologist (SYF). The team also considered various aspects of Taiwanese culture when developing specific content. The initial version of the booklet included (1) life story, (2) current health status and health habits, (3) life-threatening conditions and suffering, (4) medical decisions about end-of-life care, and (5) various other aspects.

#### Stage 2: expert evaluation

We invited six experts in palliative care to rate the appropriateness of the content of the initial ACP booklet using a 4-point Likert Scale (where 1 = not relevant, 2 = somewhat relevant but needs major revision, 3 = quite relevant but needs minor revision, 4 = highly relevant). The items with a rating of either 3 or 4 were considered relevant, and a content validity index (CVI) was calculated for each of these items [39,40]. Additional comments and suggestions were also collected. The six experts were all female nursing professionals aged 32 to 48 years. Five of them had a master degree. Their work experience in palliative care ranged from 6 to 20 years. The detailed characteristics of the experts are presented in [Table 1](#).

#### Stage 3: focus groups

The goals of the focus groups were to review the ACP booklet and provide user experience. The focus groups [41] included nine healthy people who had experience in discussing ACP issues, including one nurse, two social workers, and six senior hospice volunteers (all females). The authors (SCW and SYF) led the focus group sessions, which were conducted four times, lasting more than 9 hours in total. The participants read the ACP booklet prior to the session. The interview guides included: (1) the important things in one's current life and future, (2) worries about health and illness, (3) concerns and preferences about end-of-life care, (4)

**Table 1**  
Demographic characteristics of the experts.

Case ID	Age (y)	Sex	Education	Position	Years in palliative care
A	32	Female	PhD	Executive of Secretary of the Palliative Nursing Association	8
B	38	Female	Master	Head nurse	17
C	43	Female	Master	Head nurse	17
D	32	Female	Master	Nurse	6
E	48	Female	Master	Head nurse	20
F	37	Female	Master	Supervisor of nurses	15

preparation for death and dying, and (5) their experience when discussing ACP issues, as well as suggestions about the ACP booklet.

All the discussions were recorded and transcribed *verbatim*. The data analysis consisted of content analysis [42]. The main focus of this study was to develop the ACP booklet. Therefore, only the results related to ACP experiences and suggestions were selected, including important information that should be included in the booklet, the wording of the items, and the types of questions. The viewpoints of the healthcare professionals and healthy people were integrated into the booklet. The significant ACP issues that were identified by the focus groups are presented in this paper.

### 3. Results

Five domains were identified with reference to ACP. First, the life story section; this section guides people to review the important events during their lifetime, such as study, love, marriage, career, achievements, and retirement. Second, the section on current health status and health habits; this guides people to review their health habits and whether they have any specific chronic illness, as well as comparing the present moment with their status last year and with their peers of the same age. Third, the section on life-threatening conditions and suffering; this lists the common problems that may occur at the end of life and allow people rate how difficult these situations are. The items included disabilities, functional impairment, medical procedures and treatments, and dependence on others. Fourth, the section on medical decisions related to end-of-life care; this section lists various life-sustaining treatments, including artificial nutrition, endotracheal intubation, cardiopulmonary resuscitation (CPR) or DNR, dialysis, comfort care, and palliative care. People should make decisions whether they want these during serious illness, including when they are in a coma, if they are suffering from dementia, or when they are at the terminal stage of an illness. Additional information about medical treatment is also provided. The final other item section consisted of

issues such as surrogate decision makers and ACP, financial arrangements, the funeral ceremony and religious rites, the burial place and rites, and any memorial event. The CVIs ranged from 0.73 to 1.00. Details of the contents of these domains and CVIs are presented in Table 2.

#### 3.1. Feedback from a healthy population

All participants had experience of caring for terminal patients and were willing to discuss ACP with physicians, families, and friends. They were motivated to do this, not only for themselves, but also for their families. "It is a good thing to prepare for death early; you never know when it will come. This is most important because your relatives and children might struggle and feel pain if they do not know what you want and how to make decisions for you when you are dying" (62 years, female, volunteer).

The participants mentioned medical and nonmedical issues related to end-of-life care. Medical issues involved all the medical decisions that need to be made during the end of life, such as artificial nutrition, endotracheal intubation, and CPR and DNR. Participants focused on the benefits, risks, and consequences of these medical procedures. In addition, they worried about the disability that accompanies terminal illness, such as loss of consciousness, loss of control, uselessness, dependence on others, and the inability of others to take care of them.

The nonmedical issues covered the broad aspects of life and interpersonal relationships. These included the ways to deal with dying and death, making arrangements for their family, communication with family and friends, money and financial problems, and the funeral ceremony and religious rites. "At that moment, you will review your life and try to figure out what is the meaning of your own life; meanwhile you have to think ahead and prepare what will happen in future" (55 years, female, volunteer).

Most of the participants mentioned that ACP decision-making was difficult because of the uncertainty associated with terminal medical conditions. They did not have medical knowledge related

**Table 2**  
Contents of the ACP booklet and CVIs.

Category	Content	CVI
Life story	Childhood: my aspirations/ambitions, interests, habits and best friends Youth: my learning, love, marriage Adulthood: my family, career, life and proudest achievements Old age: life during retirement Life story: the things that I want to do the most; the things I am most concerned about; the things I regret in my life; and the purpose and meaning of my life	1
Current health status and health habits	Specific chronic diseases, subjective evaluation of my health status and the good and bad health habits that I have	0.92
Life threatening conditions and suffering	Cannot walk, lie on a bed, cannot move the body, incontinence, have painful symptoms, depending on others, having become a burden on other, no one takes care of me, and have financial problems	0.73
Medical decisions about end-of-life care	Artificial nutrition, endotracheal intubation, cardiopulmonary resuscitation (CPR), do not resuscitate (DNR), hospice palliative care and place of death.	0.96
Various other items	Surrogate decision maker regarding ACP, financial arrangements, the funeral ceremony and related religious rites, the burial place and rites, and a photo and memorial service	0.86

ACP = advance care planning; CVI = content validity index.

to the prognosis of illnesses and did not know the pros and cons of CPR. Moreover, doctors were unable to give them exact answers. This led to the struggles with the issue and difficulty with decision-making. “Sometimes it is not known what endotracheal intubation is and what are its benefits. Maybe...maybe patients can recover after it is removed. It depends on the doctors' judgment, but they only tell you the possibility. The most difficult is that you have to make choice on your own” (57 years, female, social worker).

Therefore, the participants considered complete information about CPR, artificial nutrition, endotracheal intubation, and palliative care to be necessary. They reported that it should include the procedure, its outcomes and effects, the consequences of not receiving the treatment, and alternative treatment options. “About CPR, you can describe the procedures of CPR, and what are the short-term and long-term consequences if receiving CPR; and without CPR, what will happen, and what kinds of care medical staff will provide. You can give the full information in this book and let people choose” (43 years, female, nurse).

All participants expressed the feeling that, because of the complexity and difficulty of end-of-life decisions, an ACP booklet that can guide discussion would facilitate decision-making. They also had many suggestions about the wording, types of questions, and characteristics of the information to be provided. According to them, a positive and neutral description was better, and open-ended questions should be used that are able to guide people to begin thinking. For example, about hydration and nutrition, “You can use brief, gentle, and neutral descriptions, such as ‘the decline and dying are natural, and the patient can decide when he/she wants to eat’ instead of ‘too much hydration and nutrition would increase patients’ burden and pain’” (55 years, female, volunteer).

#### 4. Discussion

In this study we developed an ACP booklet and explored the significant issues related to ACP in Taiwan. The important issues included life story, current health status and health habits, life-threatening conditions and suffering, medical decisions related to end-of-life care, and various other items. It was also found that people sought complete information about treatment procedures, the benefits of such treatments, the cost of such treatments, and the alternative care available if they did not want aggressive treatment such as CPR.

Both medical and personal issues needed to be addressed in an ACP discussion, the most important ones being the medical condition of the individual and his/her prognosis. Participants indicated that they would like to know their condition, whether they were dying, the medical procedures available, and the benefits and costs of these procedures. Relevant important medical decisions included artificial nutrition, endotracheal intubation, CPR, and DNR. People have to decide if CPR and endotracheal intubation should be used when they are dying. Artificial nutrition involves concepts related to food and nutrition. In Taiwan, many people believe that patients need enough nutrition to fight the illness and worry that insufficient nutrition may lead to an earlier death [43]. In addition, another important medical decision is the need for patients to decide whether they should receive palliative care or aggressive treatment.

Thus, complete information should be given, including the benefits and consequences of any special treatment, as well as alternative care options. For example, the pros and cons of CPR should be explained, as well as the benefits and consequences of DNR, or if patients do not receive CPR prior to dying, then what other treatment and care, such as palliative and comfort care, could be provided to them. Additionally, if too much artificial hydration

and nutrition might increase the burden of the patient [44], then the alternatives about what physicians and families can do for such a patient should be presented in the booklet.

In addition to medical decisions, there are still many personal and interpersonal issues that arise at the end of life. People facing death have to think about issues such as which person can take care of them and be a surrogate decision maker, the place where end-of-life care is to be provided, the funeral ceremony, the burial place, and the rites to be used. Additionally, interpersonal issues also need to be considered. People might wish to arrange for relatives or others to take care of their children or parents and deal with the financial issues and inheritance, as well as review their lives and express love, apology, thanks, and goodbye [45].

People's preferences, values, and beliefs, which are shaped by culture, may influence any ACP discussion. This involves the concepts of a good death and the preparations for dying [46]. For example, there is a stereotype against DNR—that it means giving up [31], there are myths about nutrition and hydration being related to the progress of the illness [43], and there is a tendency to prefer to die at home [47]. There are no correct or wrong choices, but they need to be based on the patient and family preferences, their wishes, and their life context. People can think about the ACP issues and prepare for death in advance in order to achieve a good life and a good death, which, in Taiwanese culture, mean a satisfactory, integrated, and full life without regret.

Most participants in the focus groups mentioned the difficulties of having ACP discussions with healthy people in the community, especially because of the taboo related to death and uncertainty of medical situations. The structure of this booklet could help to guide the discussions from nonthreatening topics to the end-of-life issues. Life story and health habits should lead users to think about their health status, and the values and beliefs that make up their lives. Subsequently, the information about the critical medical problems should lead them to think about the way they would like to leave the world, based on their preferences and wishes. In addition, the types and characteristics of the provided information play an important role in any ACP discussion. Open-ended questions are able to guide the discussion and help the users to explore their preferences and values about end-of-life care or life-sustaining treatment [34]; this seems to be preferable to questionnaire-based items.

Thus, approaches to discussing ACP are an important issue when promoting the concept of ACP. First, with reference to interpersonal relationships, people usually like to discuss these issues with someone they are familiar with. Second, it is important to focus on the preferences and values related to end-of-life care and a good death rather than on specific dying situations. There are too many complications and treatment decisions that are to be made at the end of life, and people may not have the relevant knowledge and information. Therefore, it is impractical to ask people to consider all the potential conditions related to terminal illness. Furthermore, the preferences and values of individuals are most important when determining what type of end-of-life care they want and how they wish to spend the last period of their life [34]. Third, it is important to ensure that continuous discussion takes place. Preferences and decisions about ACP might change based on the experience of the patient and significance of others' opinions. Therefore, further discussions with families and proxies, and a continuous revision of the ACP are necessary.

It is necessary in the future to determine the effectiveness of the booklet. Further studies should test whether this educational material improves the rate of advance directives completion. The booklet will also help to develop discussion guidelines for ACP in the context of Taiwanese culture.

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## References

- [1] NHS. Advance care planning: a guide for health and social care staff. London: National End of Life Care Programme; 2008.
- [2] Miles SH, Koepf R, Weber EP. Advance end-of-life treatment planning. A research review. *Arch Intern Med* 1996;156:1062–8.
- [3] Beauchamp TL, Childress JF. Principles of biomedical ethics. 5th ed. New York: Oxford University Press; 2001.
- [4] Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med* 2007;147:51–7.
- [5] Thomas K, Lobo B. Advance care planning in end of life care. New York: Oxford University Press; 2011.
- [6] DoH. Hospice-Palliative Care Act, 2004. Available at: [http://www.doh.gov.tw/EN2006/DM/DM1\\_p01.aspx?class\\_no=246&now\\_fod\\_list\\_no=246&level\\_no=1&doc\\_no=39735](http://www.doh.gov.tw/EN2006/DM/DM1_p01.aspx?class_no=246&now_fod_list_no=246&level_no=1&doc_no=39735). [accessed 06.02.13].
- [7] Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211–8.
- [8] Degenholtz HB, Rhee Y, Arnold RM. Brief communication: the relationship between having a living will and dying in place. *Ann Intern Med* 2004;141:113–7.
- [9] Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc* 2007;55:189–94.
- [10] Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med* 2004;59:57–68.
- [11] Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care—a case for greater use. *N Engl J Med* 1991;324:889–95.
- [12] Ahalt C, Walter LC, Yourman L, Eng C, Pérez-Stable EJ, Smith AK. “Knowing is better”: preferences of diverse older adults for discussing prognosis. *J Gen Intern Med* 2012;27:568–75.
- [13] Tang CN, Wang YW, Hsieh JG, Fan SY. Do-Not-Resuscitate order and allowed natural death: the titles and information contents related to decision. *Taiwan J Hosp Palliat Care* 2015. in press.
- [14] Royal College of Physicians. Concise guidance to good practice — Advance care planning. 2009. Available at: <http://www.rcplondon.ac.uk> [accessed 07.01.13].
- [15] Terry M, Zweig S. Prevalence of advance directives and do-not-resuscitate orders in community nursing facilities. *Arch Fam Med* 1994;3:141–5.
- [16] Lo YT, Wang JJ, Liu LF, Wang CN. Prevalence and related factors of do-not-resuscitate directives among nursing home residents in Taiwan. *J Am Med Dir Assoc* 2010;11:436–42.
- [17] Hsu CP, Chen HW, Lee SY, Tsou MT. Knowledge and attitude toward hospice palliative care among community-dwelling aged Taiwanese—analysis of related factors. *Int J Gerontol* 2012;6:105–11.
- [18] Glick KL, Mackay KM, Balasingam S, Dolan KR, Casper-Isaac S. Advance directives: barriers to completion. *J N Y State Nurses Assoc* 1998;29:4–8.
- [19] Hu WY, Huang CH, Chiu TY, Hung SH, Peng JK, Chen CY. Factors that influence the participation of healthcare professionals in advance care planning for patients with terminal cancer: a nationwide survey in Taiwan. *Soc Sci Med* 2010;70:1701–4.
- [20] Tamayo-Velazquez MI, Simon-Lorda P, Villegas-Portero R, Higuera-Callejón C, García-Gutiérrez JF, Martínez-Pecino F, et al. Interventions to promote the use of advance directives: an overview of systematic reviews. *Patient Educ Couns* 2010;80:10–20.
- [21] Patel RV, Sinuff T, Cook DJ. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *J Crit Care* 2004;19:1–9.
- [22] Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? *J Am Geriatr Soc* 2007;55:277–83.
- [23] Austin CA, Mohottige D, Sudore RL, Smith AK, Hanson LC. Tools to promote shared decision making in serious illness: a systematic review. *JAMA Intern Med* 2015;175:1213–21.
- [24] Jain A, Corriveau S, Quinn K, Gardhouse A, Vegas DB, You JJ. Video decision aids to assist with advance care planning: a systematic review and meta-analysis. *BMJ Open* 2015;5:e007491.
- [25] Jezewski MA, Meeker MA, Sessanna L, Finnell DS. The effectiveness of interventions to increase advance directive completion rates. *J Aging Health* 2007;19:519–36.
- [26] Durbin CR, Fish AF, Bachman JA, Smith KV. Systematic review of educational interventions for improving advance directive completion. *J Nurs Scholarsh* 2010;42:234–41.
- [27] Bravo G, Dubois MF, Wagener B. Assessing the effectiveness of interventions to promote advance directives among older adults: a systematic review and multi-level analysis. *Soc Sci Med* 2008;67:1122–32.
- [28] Kelly B, Rid A, Wendler D. Systematic review: individuals' goals for surrogate decision-making. *J Am Geriatr Soc* 2012;60:884–95.
- [29] Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: “you got to go where he lives”. *JAMA* 2001;286:2993–3001.
- [30] Huang CH, Hu WY, Chiu TY, Chen CY. The practicalities of terminally ill patients signing their own DNR orders—a study in Taiwan. *J Med Ethics* 2008;34:336–40.
- [31] Chiu TY, Hu WY, Cheng SY, Chen CY. Ethical dilemmas in palliative care: a study in Taiwan. *J Med Ethics* 2000;26:353–7.
- [32] Messinger-Rapport BJ, Baum EE, Smith ML. Advance care planning: beyond the living will. *Cleve Clin J Med* 2009;76:276–85.
- [33] Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med* 2010;153:256–61.
- [34] Pearlman RA, Cole WG, Patrick DL, Starks HE, Cain KC. Advance care planning: eliciting patient preferences for life-sustaining treatment. *Patient Educ Couns* 1995;26:353–61.
- [35] Pearlman R, Starks H, Cain K, Rosengreen D, Patrick D. Your life, your choices: planning for future medical decisions. DIANE Publishing; 2010.
- [36] Towey J. Five wishes. Aging with dignity. Robert Wood Johnson Foundation; 1997.
- [37] Molloy W. Let me decide: the health and personal care directive that speaks for you when you can't. Troy, Ont.: Newgrange; 2002.
- [38] Chan HY, Pang S. Readiness of Chinese frail old age home residents towards end-of-life care decision making. *J Clin Nurs* 2011;20:1454–61.
- [39] Lynn MR. Determination and quantification of content validity. *Nurs Res* 1986;35:382–5.
- [40] Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health* 2006;29:489–97.
- [41] Sim J. Collecting and analysing qualitative data: issues raised by the focus group. *J Adv Nurs* 1998;28:345–52.
- [42] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
- [43] Chiu TY, Hu WY, Chuang RB, Chen CY. Nutrition and hydration for terminal cancer patients in Taiwan. *Support Care Cancer* 2002;10:630–6.
- [44] Winter SM. Terminal nutrition: framing the debate for the withdrawal of nutritional support in terminally ill patients. *Am J Med* 2000;109:723–6.
- [45] Fu L, Deng D, Zhao YX, Wu X, Zhou YF. Loving, thanks, apology and adieu: effect of death education among hospice patients. *Drug Eval* 2012;9:13.
- [46] Chao CS. The meaning of a good death for terminally ill cancer patients in Taiwan. *J Nurs* 1997;44:48–55.
- [47] Tang ST. Meanings of dying at home for Chinese patients in Taiwan with terminal cancer: a literature review. *Cancer Nurs* 2000;23:367.