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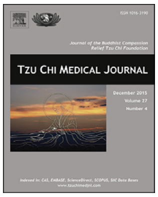

Original Article

Development of an advance care planning booklet in Taiwan

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A R T I C L E I N F O

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A B S T R A C T

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.

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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Conflicts of interest: none.

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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)