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Original Study

Advance Directive and End-of-Life Care Preferences Among Nursing Home Residents in Wuhan, China: A Cross-Sectional Study

Ping Ni PhD(c) [a], Jing Zhou BS [a], Zhao Xi Wang BS [a], Rong Nie PhD(c) [a], Jane Phillips PhD [b], Jing Mao PhD [a,*]

[a] School of Nursing, Tongji Medical College, Huazhong University of Science and Technology, Wuhan, Hubei, China
[b] Faculty of Health, University of Technology Sydney, Sydney, Australia

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A B S T R A C T

Objectives: To describe Chinese nursing home residents' knowledge of advance directive (AD) and end-of-life care preferences and to explore the predictors of their preference for AD.
Design: Population-based cross-sectional survey.
Settings: Nursing homes (n = 31) in Wuhan, Mainland Southern China.
Participants: Cognitively intact nursing home residents (n = 467) older than 60 years.
Measures: Face-to-face questionnaire interviews were used to collect information on demographics, chronic diseases, life-sustaining treatment, AD, and other end-of-life care preferences.
Results: Most (95.3%) had never heard of AD, and fewer than one-third (31.5%) preferred to make an AD. More than half (52.5%) would receive life-sustaining treatment if they sustained a life-threatening condition. Fewer than one-half (43.3%) chose doctors as the surrogate decision maker about life-sustaining treatment, whereas most (78.8%) nominated their eldest son or daughter as their proxy. More than half (58.2%) wanted to live and die in their present nursing homes. The significant independent predictors of AD preference included having heard of AD before (odds ratio [OR] 9.323), having definite answers of receiving (OR 3.433) or rejecting (OR 2.530) life-sustaining treatment, and higher Cumulative Illness Rating Scale score (OR 1.098).
Conclusions: Most nursing home residents did not know about AD, and nearly one-third showed positive attitudes toward it. AD should be promoted in mainland China. Education of residents, the proxy decision maker, and nursing home staff on AD is very important. Necessary policy support, legislation, or practice guidelines about AD should be made with flexibility to respect nursing home residents' rights in mainland China.

With the aging of China's population, the demand for nursing home care is increasing.[1] In Wuhan, a southern city in Hubei province, Mainland China, there are approximately 9.79 million people.[2] The number of people older than 65 years in China is projected to increase from its current level of 8.9%[3] to 23.0% by 2050.[4] Although few (1.49%) older people currently live in nursing homes in mainland China,[4] it is anticipated that a combination of China's "4-2-1" (1-child policy) or "4-2-2" (some couples can have 2 children if only 1 or neither of the pair has siblings) family structure and industrialization[5] will see larger numbers of older people moving into nursing homes.[6] Although nursing home residents are frailer than those living in their own homes,[6] few studies have investigated the end-of-life care preferences of older Chinese people living in nursing homes.[7] A recent study involving older Chinese people living in Hong Kong nursing homes found that most did not desire cardiopulmonary resuscitation (CPR) (61%) or artificial nutrition or hydration (74%) to be initiated.[7] Another Hong Kong study identified that many nursing home residents were uncertain or uncomfortable when asked about stating their preferences for life-sustaining treatment, with many leaving this question unanswered.[6]

In traditional Chinese culture, death is a very sensitive issue, and a topic to be avoided, with those who do mention death considered sacrilegious.[8] Most older Chinese people consult their relatives, especially their oldest son, before making health care decisions. For example, traditional Taiwanese believe their eldest son is responsible for arranging the rest of their life.[9] In a rapidly developing country like China, it is challenging to integrate traditional values and advance care planning processes into the existing health care system.

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* Address correspondence to Jing Mao, PhD, School of Nursing, Tongji Medical College, Huazhong University of Science and Technology, Number 13, Hangkong Road, Qiaokou District, Wuhan, Hubei, China.
E-mail address: maojing@hust.edu.cn (J. Mao).

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Globally, there is a push to ensure that more people prospectively document their end-of-life care preferences, often in the form of an advance directive (AD).[10–12] An AD is a legal document that outlines a person's care preferences and wishes, should their decision-making ability be diminished as a result of a critical illness or cognitive impairment.[13,14] Unlike other parts of the developed world (ie, United States,[15] Netherlands,[16] Australia,[12] United Kingdom,[11] and Singapore[17]), the concept of AD is still relatively new in mainland China. However, in other parts of China, there is growing interest and concern about the need for better end-of-life care for terminally ill older patients, which is reflected in various recent policy initiatives. For example, in June 2007, the Hong Kong Law Reform Commission issued a Consultation paper on "Substitute Decision Making and AD," detailing that doctors must comply with a patient's AD and end-of-life preferences.[18] In Taiwan, the Hospice-Palliative Care Act (2002) aims to ensure that the end-of-life medical wishes of patients are respected and end-of-life care is provided in accordance with recommended clinical guidelines.[19,20] In mainland China, palliative care is developing slowly and there is currently no case law regarding AD. In mid-2013, the Beijing Advance Directive Promotion Association was established with the approval of the Beijing Civil Affairs Bureau.[21] Charged by the Beijing Ministry of Health, this organization aims to promote the uptake of AD in China, inform Chinese people of their rights to prospectively define their end-of-life care preferences, and to enhance care of the dying.[21] Given the paucity of information and limited published data on AD and end-of-life care preferences among older adults in mainland China, this study sought to describe mainland Chinese nursing home residents' knowledge of AD and their end-of-life care preferences, and to identify predictors of their AD preferences.

Methods

Study Design and Participants

This study adopted a cross-sectional study design using a cluster sampling method. Ethical approval of the research protocol was granted by the institutional review board of the Huazhong University of Science and Technology as well as from all institutional review boards of participating nursing homes. This study was conducted over an 11-month period, from December 1, 2012, to October 31, 2013.

The study involved 8 of 13 regions of Wuhan (Wu Chang, Qiao Kou, Jiang Han, Jiang An, Hong Shan, Dong Xi Hu, Qing Shan, and Han Yang), mainland China. All nursing homes in these regions were invited to be involved in the study. Once the nursing homes agreed to participate, all elderly residents in these nursing homes were screened for eligibility, using the following inclusion criteria: older than 60 years, Chinese-speaking, and made 3 or less errors on the Chinese Version-Short Portable Mental Status Questionnaire (SPMSQ).[22] Residents with known psychiatric or cognitive problems and/or communication difficulties were excluded from the study.

Data Collection

A member of the research team, a trained nurse facilitator, collected the quantitative data, including demographic data from participants during a 45-minute face-to-face interview and administered the following validated instruments (Table 1). The Chinese Version of the Cumulative Illness Rating Scale (CIRS)[6] was used to capture comorbid conditions, which were confirmed by the medical record. Physical functional status was collected using the Chinese version of Personal Activity of Daily Living (P-ADL) and Instrumental Activity of Daily Living (I-ADL); the score of P-ADL or I-ADL was the sum value of all 8 items in each scale which range from 8 to 24.[23] The Quality-of-Life Concerns in the End-of-Life Questionnaire (QOLC-E) was also administered.[24] Participants' preferences for various life-sustaining treatment were elicited by asking the following question: "*If you were severely ill or even in a life-threatening condition in which life-sustaining treatment could only help you to sustain your life but cannot recover your health, would you like to accept it?*" Participants were also asked other specific questions exploring their preferences related to AD and end-of-life care.

Data Analysis

The Statistical Package for Social Sciences (SPSS) version 17.0 for Windows (IBM SPSS Statistics, IBM Corporation, Chicago, IL) was used for the quantitative data analyses. The participants' characteristics and their responses to each of the questions were analyzed by descriptive statistics first. For the question "*If you have the chance to make an AD, would you be willing to make it?*" (refer to question 2 in Table 2), the 4 possible responses were merged accordingly: "Willing" and "Fairly willing" (Willing), "Reluctant" and "Fairly reluctant" (Reluctant). Chi-square test and *t* test were used for categorical and continuous variables, respectively. Bivariate analyses were used to examine the associations of sociodemographic characteristics, chronic diseases, and other factors with the preference for AD. Factors significant previously in univariate analyses were included in the binary forward (likelihood ratio) logistic regression analyses models (binary logistic regression is the statistics method, forward: likelihood ratio is the variable selection method), all adjusted for age and sex. The dependent variable was the preference for AD and the independent variables were factors with $P < .05$ in previous bivariate analyses.

Results

A total of 31 (62%) of 50 nursing homes participated in the study. Of the 501 participants identified as eligible to participate, 489 (97.6%) gave written informed consent. Of the 489 consenting participants, 22 interviews were subsequently ceased, as the participants became too distressed (n = 12) or too tired (n = 10) to continue, leaving 467 participants.

Demographics

The demographic characteristics of the 467 participants are reported in Table 1. No significant difference was found in sex, mean age, and education level between those who agreed (n = 489) and refused (n = 12) to participate in the study. Of the recruited participants, more than half (59.5%) were women, and the mean age (±SD) was 77.0 ± 8.527 years. Most were widowed (85.7%) and most (85.4%) lived in private nursing homes. Half (52.9%) had health insurance. Nearly three-quarters (73.7%) were educated to the elementary school level or higher, whereas a quarter (26.3%) had never been to school. Nearly all perceived they had "good/general good relationship with family" (91.9%) and other residents (86.5%). In accordance with Chinese culture, half (50.1%) had a belief that their ancestors lived in another world, and they would be protected by the ancestors if they remember and memorialize them ("ancestor worship"). Most (67.9%) self-rated their health as being "generally good," with hypertension (48.0%), insomnia (18.2%), and stroke (18.0%) ranked as the top 3 most common chronic diseases/conditions. The QOLC-E score for the sample was (mean ± SD) 3.23 ± 0.48, the I-ADL and P-ADL scores were 12.91 ± 4.27 and 20.78 ± 4.74, respectively, and the CIRS score was 4.23 ± 2.98 (Table 1).

Knowledge and Preferences for AD and End-of-Life Care

Most (95.3%) had never heard of AD, and fewer than a third (31.5%) were "willing/fairly willing" to make an AD, and the main