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Original Study

Attitudes Toward Advance Directives Among Patients and Their Family Members in China

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ABSTRACT

Keywords:

Advance care planning
advance directives
Asia

Objectives: Chinese people are generally unfamiliar with the concept of advance care planning or advance directives (ACP/ADs), which raises dilemmas in life-support choice and can even affect clinical decision making. To understand and address the issues involved better, we investigated the awareness of ACP/ADs in China, as well as people's attitudes toward medical autonomy and end-of-life care.

Design: A multicenter cross-sectional survey, conducted from August 1 to December 31, 2016.

Setting: Twenty-five hospitals located in 15 different provinces throughout mainland China.

The authors declare no conflicts of interest.

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Participants: Pairs of adult patients without dementia or malignancies, and a family member.

Measurements: Participants self-filled anonymous questionnaires, and the data collected were analyzed to relate patients' sociodemographic characteristics to their awareness of ACP/ADs and attitudes to health care autonomy and end-of-life care.

Results: Among 1084 patients who completed the questionnaire, 415 (38.3%) had heard about ACP/ADs. Having been informed about ACP/ADs, 995 (91.8%) were willing to find out their true health status and decide for themselves; 549 (50.6%) wanted to institute ACP/ADs. Regarding end-of-life care, 473 (43.6%) chose Do Not Resuscitate, and 435 (40.1%) wished to forgo life-support treatment if irreversibly moribund. Patients predominantly (481, 44.4%) chose general hospital as their preferred place to spend their last days of life; only 114 (10.5%) favored a special hospice facility. Patients' main concerns during end-of-life care were symptom control (35.1%), followed by functional maintenance and quality of life (29.8%), and prolonging life (18.9%). More highly educated patients had significantly greater awareness of ACP/ADs than less well educated ones ($\chi^2 = 59.22$, $P < .001$) and were more willing to find out the truth for themselves ($\chi^2 = 58.30$, $P \leq .001$) and make medical decisions in advance ($\chi^2 = 55.92$, $P < .001$). Younger patients were also more willing than older ones to know the truth ($\chi^2 = 38.23$, $P = .001$) and make medical decisions in advance ($\chi^2 = 18.42$, $P = .018$), and were also more likely to wish to die at home ($\chi^2 = 96.25$, $P < .001$). Only 212 patients' family members (19.6%) wanted life-support treatment for themselves if irreversibly moribund, whereas 592 (54.6%) would want their relative to receive such procedures in the same circumstances; a similar discrepancy was evident for end-of-life invasive treatment (18.3% vs 42.7%).

Conclusions: Awareness about ACP/ADs in China is still low. Providing culturally sensitive knowledge, education, and communication regarding ACP/ADs is a feasible first step to promoting this sociomedical practice.

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In 2004, the World Health Organization defined “advance care planning” (ACP) as a process of “planning in advance for decisions that may have to be made, prior to incapability or at the end of life.”¹ An “Advance Directive” (AD) is a formal document that nominates the patient's substitute decision maker (power of attorney for personal care) and/or details their wishes regarding life-sustaining treatment through a living will.^{2,3} Previous studies have confirmed that ACP/ADs enable patients to receive the care that they really want.² ACP/ADs have been widely used in many countries and have legal support; the United States Patient Self-Determination Act (1991) makes it clear that patients have the right to know their condition and choose how they will be treated, and also recognizes the legitimacy of written ADs—it also requires medical staff to inform patients about ACP.⁴ In China, on the other hand, ACP/ADs are rarely mentioned, and there are still no relevant legal requirements. For example, if a patient has a malignancy, many caregivers will choose not to divulge this to the patient but plan his or her treatment instead. When patients lose the capacity to make medical decisions, their family members must decide the next step; however, patients and their family members very seldom talk about death, end-of-life support, and related issues. Hence, a patient's family does not always know what their relative wants and sometimes make choices contrary to the patient's real wishes.

As China faces the “Silver Tsunami,” the concept of ACP/ADs has been receiving more and more attention. Because the general public still lack awareness about ACP/ADs, we designed this survey to gain a preliminary understanding of Chinese people's awareness about ACP/ADs, and their attitude to health care autonomy, as well as end-of-life care. We also discuss the feasibility of implementing ACP/ADs.

Methods

Participants

Adult patients aged ≥ 18 years without dementia or malignancies were recruited from 25 hospitals in 15 different provinces and cities throughout mainland China. Individual patients and a family member were asked during outpatient or inpatient visits if they were willing to complete a survey about ACP/ADs.

Study Design

This multicenter cross-sectional survey was conducted from August 1 to December 31, 2016. Professors from the Geriatric Department of Peking Union Medical College Hospital reviewed and approved the study questionnaire, and the Peking Union Medical College Hospital Ethics Committee approved the protocol (S-K127).

All data were collected from self-filled anonymized reports completed during face-to-face interviews—Questionnaire A by patients and a matched Questionnaire B by family members. Questionnaire items comprised sociodemographic characteristics (age, sex, religion, education level, residential situation, etc) and 6 questions designed to reflect participants' awareness, preferences, and attitudes toward ACP, knowing the truth, health care autonomy, and end-of-life care. Before answering, participants were introduced to the concept of ACP/ADs: “Advance care planning is defined as a communication and decision-making process that allows individuals to clarify their values and preferences for future care in advance when they are healthy and conscious, and enables them to communicate their wishes to their loved ones and surrogate decision-makers and healthcare providers.”⁵ After this explanation, patients were asked the following questions, Q1 to Q4, requiring yes/no answers.

- **Q1:** Do you want to know your real medical condition (including bad news) and take medical decisions for yourself?
- **Q2:** Decisions in special circumstances: If you cannot make medical decisions due to a medical problem (such as coma), are you willing to institute advance care planning/Advance Directives?
- **Q3:** Do you want end-of-life invasive treatment measures (including electric defibrillation, extracorporeal compression, tracheal intubation, ventilator-assisted ventilation, tracheotomy) if such can only delay your death, with no chance of recovery?
- **Q4:** Do you want life-support treatment (including nutritional support such as tube feeding or percutaneous endoscopic gastrojejunostomy, broad-spectrum antibiotics, blood transfusion, hemodialysis) if you have late-stage Alzheimer or are in a persistent vegetative state?

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