

Original Article

Exploring the Issues of Advance Directives in Patients with Mild Dementia in Taiwan

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Due to cultural traditions, most Taiwanese do not have an advance directive or healthcare proxy. We explored how patients with mild dementia in Taiwan may still make self-determined decisions concerning advance directives for their healthcare and end-of-life care choices as the disease progresses. We examined 260 respondents with mild dementia at a Taiwan medical center: 199 patients who agreed (and 61 patients who disagreed) with the concept of advance directives completed a structured questionnaire. Multiple logistic regression models to determine the between-group differences revealed that the following were positively associated with approval of end-of-life directives: maintaining one's quality of life (adjusted odds ratio [AOR], 2.44; 95% CI: 1.07-5.53), discussion with family members (AOR, 3.50; 95% CI: 1.49-8.26), and friend support networks (AOR, 3.36; 95% CI: 1.34-8.43). Cardiopulmonary resuscitation (AOR, 0.27; 95% CI: 0.09-0.79) was negatively associated with approval. There was also a positive association between the support of the legal validity of end-of-life directives (OR, 1.93; 95% CI: 1.07-3.48), without other confounding factors. In Taiwanese society, we remain mindful of cultural influences that may impact patients, including maintaining one's quality of life, discussion with family members, and friend/support networks. These influences may help dementia patients complete their advance directives.

Key words: advance directive, dementia, patient autonomy, quality of life, culture

Dementia is a progressive cognitive impairment. When individuals with dementia are at the end of their lives, it may be necessary to provide them with life-sustaining treatment or aggressive interventions [1]. In Taiwan, the use of such interventions often leads to deep conflicts between Taiwanese societal traditions and the wishes of family members. The care of advanced dementia patients should be geared toward palliative support and maintaining the patient's quality of life [2]. However, contradictions and conflicts between an individual patient's values and those of the people surrounding the patient can exacerbate an already emotionally and phys-

ically difficult process [3]. As individuals' dementia evolves, their personalities may change, and they may become unresponsive or unable to communicate with others, which negatively affects their care and healthcare decisions [4].

It is important that dementia patients retain their independent decision-making abilities as much as possible, and they should express their preferences about end-of-life decisions and the way they want to be looked after in the future [5]. Family members and medical personnel should respect the patient's right to seek treatment and should develop and use measures that enable patients' autonomy in obtaining the type of med-

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ical care and medical ethics they need [6].

Ideally, when making decisions, the patient thinks about his or her health situation and plans for the future and considers whether he or she has a comprehensive care plan for the end of life, and the patient actively participates in care decisions with surrogates and the medical team. However, this type of proactive planning is not universal. For example, the implementation of advance directives is not yet accepted by Taiwan society as a whole [7], reflecting perhaps some differences between Eastern and Western cultures [8,9]. Taiwan has a typically Eastern society that is influenced by Buddhism, Taoism and Confucianism [10]. Under such influences, it is a matter of some discomfort in Taiwan — if not downright forbidden — to talk to elders about their arrangements for the end of their lives. For instance, in Taiwan nursing homes, only 13-16% of residents signed do-not-resuscitate advance directives [11, 12], which is much lower than the 65-87% of U. S. residents who signed advance directives [13, 14]. We conducted the present study to investigate the attitudes and issues related to advance directives for patients with mild dementia in Taiwan, as a reference for probable influences and outcomes in Eastern societies.

Patients and Methods

This study was carried out at Chung-Shan Medical University Hospital, which is a medical center and teaching hospital in central Taiwan. The study subjects were patients who were being treated at the hospital's neurological clinic. We selected patients who scored 0.5 or 1 on the Clinical Dementia Rating (CDR) scale, indicating a state of very mild dementia and mild dementia. The CDR is a global dementia rating scale used to assess cognitive changes and determine the presence of dementia. The severity of dementia was quantified from very mild (score 0.5) to mild (score 1), moderate (score 2), and severe (score 3) [15].

After listening to an interviewer's instructions about this study, the patients with mild dementia to participate in the study and answered the questionnaire. We examined 260 respondents. The study period was from October 2017 to August 2018. The study was approved by the ethics committee of Chung-Shan Medical University Hospital (Approval no. CS18108).

Study design. This study was conducted to evaluate the subjects' approval or disapproval of the concept

of an advance directive. We used four fields to assess this variable (willingness, medical treatment, environment, and regulation) and a total of 12 questions on the questionnaire: (1) I worry that my condition can't be cured and will continue to deteriorate, leading to a poor quality of life. (2) I will discuss an advance directive with family members. (3) If I were unable to express my wishes clearly due to illness, my family members might dispute certain medical treatments for me without my advance directive. (4) If my condition cannot be cured and continues to deteriorate, leading to a reduced quality of life, I would spell out my wishes for the use of a nasogastric tube for feeding purposes in my advance directive. (5) My advance directive would spell out my wishes for the use of a tracheotomy tube if I became unexpectedly sick, or in an emergency. (6) My advance directive would spell out my wishes for the use of cardiopulmonary resuscitation (CPR) if I became unexpectedly sick, or in an emergency. (7) The value of life in our society is in conflict with the concept of the advance directive. (8) Medical institutions should provide consultations on advance directives and other related services. (9) If I set up an advance directive, my friends' attitude toward the directive will be favorable. (10) I have religious considerations concerning an advance directive. (11) The advance directive that I signed is legally valid. (12) After I sign the advance directive, I can change or remove it.

The answers were divided into categories of 'agreement' or 'disagreement'. The content validity (correlation coefficient) of this questionnaire was 0.87, and the test-retest reliability was 0.92.

Data analyses. Demographic and baseline characteristics were compared between the 'agreement' group and the 'disagreement' group, using Student's *t*-test for continuous data and the χ^2 test for discrete data. We used Spearman correlation coefficients to assess the relationship of each attitude variable. Odds ratios were estimated using binominal logistic regression. Crude odds ratios (ORs) and adjusted odds ratios (AORs) and 95% confidence intervals (CIs) were calculated for each variable. All statistics were calculated using the software SPSS 20.0 (SPSS, Chicago, IL, USA).

Results

A total of 199 patients who agreed with the concept of advance directives and 61 patients who disagreed

with the concept of advance directives were recruited into the study. The mean age was 74.79 ± 9.65 years. The patients' demographic and baseline information is summarized in Table 1, providing the characteristics of patients with dementia who agree with the process of creating an advance directives (the agreement group) versus those who do not (the disagreement group). No significant differences between the agreement and disagreement groups were observed regarding age, CDR score, gender, education level, marital status, and methods of primary care.

Table 2 provides the correlation coefficients of each factor for creating advance directives in the agreement and disagreement groups. Due to the collinearity of the variable of tracheotomy tube and CPR ($r=0.76$, $p<0.01$), we omitted the variable of tracheotomy tube in the binominal logistic regression analysis.

The results presented in Table 3 demonstrate the OR and AOR between the agreement and disagreement groups. Compared to the disagreement group, the agreement group was significantly more in the following categories: maintaining life quality (OR=2.60; 95% CI: 1.43-4.71), discussion with family (OR=5.15; 95% CI: 2.74-9.70), CPR (OR=0.49; 95% CI: 0.25-0.97), and friend support networks (OR=4.58; 95% CI:

2.35-8.92). After controlling for confounding variables, our analyses demonstrated that the agreement group was significantly more likely to make a priority of the following categories: maintaining life quality (AOR=2.44; 95% CI: 1.07-5.53), discussion with family (AOR=3.50; 95% CI: 1.49-8.26), CPR (AOR=0.27; 95% CI: 0.09-0.79), and friend support networks (AOR=3.36; 95% CI: 1.34-8.43) in contrast to the disagreement group. The variable of legal validity initially indicated a significant difference between the agreement and disagreement groups (OR=1.93; 95% CI: 1.07-3.48), but not after the adjustment for confounding variables.

Discussion

A 2018 national population survey by the Taiwanese Ministry of the Interior revealed that the percentage of the Taiwanese population aged ≥ 65 years has exceeded 14%. Due to the aging of populations, the number of dementia cases has increased in Taiwan and across the entire world. The global prevalence of dementia almost doubles within the 20 years following age 65, especially in the countries with the fastest growth of the population of elderly. Examples of locations with rapidly expanding aging populations include the Western

Table 1 Characteristics of the agreement and disagreement groups of dementia patients regarding the use of an advanced directive

Characteristics	Agreement n = 199	Disagreement n = 61	p-value
Age; mean \pm SD	74.61 \pm 9.74	75.36 \pm 9.44	0.59
CDR			
0.5; n (%)	132 (66.3)	37 (60.7)	0.42
1.0; n (%)	67 (33.7)	24 (39.3)	
Gender			
Male; n (%)	91 (45.7)	30 (49.2)	0.63
Female; n (%)	108 (54.3)	31 (50.8)	
Education level			
≤ 6 year education; n (%)	122 (61.8)	36 (59.0)	0.48
7-9 year education; n (%)	17 (8.5)	3 (4.9)	
≥ 10 year education; n (%)	59 (29.6)	22 (36.1)	
Marital status			
Unmarried/separation/divorce; n (%)	12 (6.0)	6 (10.0)	0.30
Married/cohabiting; n (%)	142 (71.4)	37 (61.7)	
Widowed; n (%)	44 (22.2)	17 (28.3)	
Methods of primary care			
Nursing home caregiver/hospital caregiver; n (%)	4 (2.0)	3 (4.9)	0.15
Self-care; n (%)	64 (32.2)	12 (19.7)	
Private caregiver; n (%)	5 (2.5)	1 (1.6)	
Families; n (%)	126 (63.3)	45 (73.8)	

Comparison was made with *t*-test for continuous data and chi-square test for discrete data.

Table 2 Correlation coefficients of each factor for creating an advanced directive group

	Keeping life quality	Discussion with families	Fearing dispute among families	Nasogastric tube	Tracheostomy tube	CPR	Social value	Hospital providing consolations	Friend support networks	Religious consideration	Legal validity	Changing willing
Keeping life quality	1											
Discussion with families	0.20**	1										
Fearing dispute among families	0.15*	0.18**	1									
Nasogastric tube	0.04	0.04	0.05	1								
Tracheostomy tube	0.08	-0.03	0.03	0.62**	1							
CPR	0.10	-0.05	0.02	0.50**	0.76**	1						
Social value	0.10	0.11	0.20**	0.03	0.20**	0.15**	1					
Hospital providing consolations	0.11	0.13*	0.05	0.05	0.08	0.08	0.03	1				
Friend support networks	0.23**	0.31**	0.07	-0.06	-0.06	-0.01	-0.02	0.22**	1			
Religious consideration	-0.08	0.04	0.20**	-0.01	-0.03	-0.00	0.28**	-0.01	-0.03	1		
Legal validity	0.08	0.13*	0.09	0.01	0.07	0.01	0.01	0.16*	0.22**	-0.05	1	
Changing willing	-0.04	0.02	0.27**	-0.06	0.01	0.07	-0.08	0.04	0.14*	0.09	0.42**	1

** $p < 0.01$, * $p < 0.05$

Table 3 Unadjusted odds ratios, adjusted odds ratios, and 95% confidence intervals for creating advanced directives in the agreement and disagreement groups

Characteristics	Agreement n=199	Disagreement n=61	OR (95% CI)	AOR (95% CI)
Willingness				
Keeping life quality; n (%)	136 (68.3)	28 (45.9)	2.60 (1.43-4.71)	2.44 (1.07-5.53)
Discussion with families; n (%)	165 (82.9)	30 (49.2)	5.15 (2.74-9.70)	3.50 (1.49-8.26)
Fearing dispute among families; n (%)	81 (40.7)	20 (32.8)	1.50 (0.82-2.77)	0.75 (0.32-1.77)
Medical treatment				
Nasogastric tube; n (%)	39 (19.6)	16 (26.2)	0.65 (0.33-1.29)	1.25 (0.42-3.73)
CPR; n (%)	34 (17.1)	17 (27.9)	0.49 (0.25-0.97)	0.27 (0.09-0.79)
Environment				
Social value; n (%)	64 (32.2)	23 (37.7)	0.78 (0.43-1.43)	1.11 (0.47-2.62)
Hospital providing consolations; n (%)	179 (90.0)	50 (82.0)	2.20 (0.87-5.61)	1.58 (0.45-5.61)
Friend support networks; n (%)	154 (77.4)	30 (49.2)	4.58 (2.35-8.92)	3.36 (1.34-8.43)
Religious consideration; n (%)	37 (18.6)	20 (32.8)	0.47 (0.24-0.89)	0.47 (0.19-1.14)
Regulation				
Legal validity; n (%)	122 (61.3)	28 (45.9)	1.93 (1.07-3.48)	0.98 (0.41-2.34)
Changing wills as wish; n (%)	103 (51.8)	20 (32.8)	1.55 (0.84-2.85)	1.32 (0.51-3.41)

Pacific and South Asia, based on the Alzheimer disease report. It estimated that the proportion of elderly Japanese aged ≥ 65 with dementia will increase from

8.0% (~ 2.7 million elderly) in 2015 to 17.1% (~ 5.3 million elderly) in 2070 [16]. A nationwide survey in Taiwan demonstrated that the prevalence of dementia

among residents aged >65 is 8.04% [17].

There have been many ethical controversies in Taiwanese society regarding the issue of advance directives. According to our present findings, even dementia patients in Taiwan who approved of signing an advance directive showed significant differences in their opinions on preserving the quality of their lives, discussing an advance directive with family members, the use of CPR, and friend and support networks. The legal validity of the directives was also a significant factor, without consideration of other factors.

Human lives can be prolonged by the many advances in high-tech medicine, but we cannot ensure an individual's quality of life at the end of that prolonged lifespan [18]. A managed plan for treatment and care at the end of life should thus be considered, including a fully briefed medical team who understands the patient's wishes as well as medical needs [19]. In the present study focusing on dementia patients with underlying CPR use, the consent of the medical team members in consideration of the patient's wishes was significantly less among the respondents who disagreed with the use of an advance directive. Treatment is the responsibility of the medical staff, but if the treatment can no longer bring benefits to the patient, there may be a conflict between how to prolong the patient's life and how to maintain the patient's quality of life [20]. Without the patient's willingness or ability to express him- or herself clearly, there is a considerable degree of difficulty in choosing a medical treatment that complies with both the patient's wishes and the protocols that are in their best interests.

Taiwan inherited an Asian culture which deems that the death of a human should be natural [21]. Taiwan's society is based on this philosophy. Taiwanese medical decisions should be family decisions, a harmonious cooperation accomplished by inviting doctors and family members to collectively make important medical decisions, not relying on only the patients themselves [7]. During the decision-making process, a patient in an Asian society is considered a member of a family [10,22]. We observed herein that the patients who planned to sign an advance directive had family members accompany them to the hospital so that the family members could participate in discussions about the advance directive. This is in contrast to Western societies' tendency to make medical decisions based on the patient's wishes and other influences [23]. In Taiwanese

society, based on the Asia culture, adult children do not take the initiative to provide advice or a discussion of an advance directive with their parents or other elders. These adult children are still subordinate to their parents and provide care without questions during the aging process [24]. Therefore, a patient with mild dementia in Taiwan who still can make lucid decisions about the future will not generally be subjected to proactive family pressure to use an advance directive. However, when the patient's dementia becomes more serious and is accompanied by the decline of other physical functions, families usually experience quarrels over the topic of an advance directive when the patient no longer has the ability to participate in the decision-making process. This is the reason why there are many family disputes over dementia-stricken patients in Taiwanese society.

Medical decisions are based on the deliberations of physicians and patients who can be involved in the decision-making process. Physicians and patients communicate information and express treatment preferences, and eventually the physician and patient agree to the treatment process after a version of 'collective bargaining' [21,25]. Our present findings revealed that even if hospitals provide advance directive services, under the Asian cultural ethos elderly Taiwanese with dementia have no concept of or intention to ask for this kind of help.

Individuals take care of their personal or private health information through a variety of strategies. One of the strategies is the disclosure of the information. Before revealing their ultimate wishes, each individual should review the disclosure content carefully, determine how to share it, with whom, and whether it will be effective for their wants and needs [26]. It is therefore natural for elderly to discuss their dilemmas and wishes with friends and obtain their support. Our results confirmed this situation to be accurate.

The Taiwanese government issued a Hospice-Palliative Care Act in 2000 to interpret advance directives in patients undergoing hospice or palliative care. This is a primary consideration for respecting the patient's medical autonomy for the terminally ill and for medical staff to act accordingly. The Patients' Right to Autonomy Act was enacted in Taiwan in 2019, and the citizens of Taiwan use health insurance to seek medical help. Every Taiwanese has a health insurance card, and according to the Patients' Right to Autonomy Act, a

patient can use an advance directive to indicate their wishes right on their health insurance card. With notations on the individual's health insurance card, once he or she is approaching the end of life and regardless of whether they are sent to any healthcare facility for emergency treatment, they can be assured that physicians will fully respect their treatment wishes, and not the wishes of the family members. The medical staff must not only consider the ethics, but also follow the regulations to complete the patient's final wish [27]. Being able to do so under the 2019 law may reduce the conflicts within many families and the conflicts between families and prevailing societal tendencies.

Taiwan's cultural traditions will of course be affected by the Patients' Right to Autonomy Act in terms of pre-establishing a physician's orders for terminally ill patients. The greatest consideration is how to effectively assist patients whose understanding of advance directives and their meaning may be limited by dementia. The most important tasks are to fully respect a terminally ill patient's wishes and support the rights and the decisions chosen for the end-of-life medical processes and protocols.

This study has some limitations. The primary limitation is that the participants, who were chosen based on CDR scores and volunteered to participate were not randomly selected. A second limitation is that the participants were from a single Taiwanese medical center. However, this patient population is very similar to those at other Taiwanese hospitals, thus potentially enhancing the representativeness of the study groups. Because Taiwanese residents visiting this hospital were not from one specific background and came from the general population, they are likely to have been representative of individuals with dementia in other areas of Taiwan.

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