

# “We Want to Sign It, But We Can't Do It”

## *Results From a Qualitative Pilot Study of Experiences Related to Advance Directives Among Families of Older Residents in a Long-term Care Facility*

Hsin-Tzu Sophie Lee, PhD ○ Chia-Ling Yang, PhD ○ Ting-Ru Chen, PhD ○  
Sei-Ven Leu, PhD ○ Wen-Yu Hu, PhD

This study aimed to clarify the experiences of family members of older adult residents regarding the signing of an advance directive in the context of a Chinese culture. Twenty family members of older residents in a long-term care facility participated in face-to-face interviews, and the researchers conducted a thematic analysis of observation field notes and interview transcripts. A content analysis of the interviews revealed 4 themes concerning the refusal to sign advance directives: resident decision, group decision, not entitled to decide, and random decision. Health providers may serve as mediators and pass on the residents' views regarding their end-of-life care to their families after holding discussions with residents and their families separately to ensure that an agreeable decision regarding the modes and objectives of EOL care is reached and that such a decision respects the right of the patient to choose.

signing an AD is an effective means of preventing unwanted hospitalization or deaths in a hospital at the EOL among nursing home residents. However, despite these benefits, family members rarely discuss ADs with nursing home residents.<sup>1</sup> Generally, ethnically Chinese people are reluctant to sign AD documents, and most consider signing ADs to be unnecessary. Regardless of whether an older adult signs the AD, they prefer to leave treatment decisions to family members to decide at the EOL.<sup>2,3</sup> In Chinese culture, EOL-related decisions are the prerogative of not only the older adult but also the family.<sup>3,4</sup> Decisions could also be made by a senior member of the family or a group of family members.<sup>5-7</sup> During such decision making, power asymmetries can be present, and they are influenced by the family members' financial capacity, education level, age, and sex; in particular, sex can play an important role because Chinese culture is traditionally patriarchal.<sup>8</sup>

An increasingly prosperous and Westernized Taiwanese society has evolved toward having such a decision-making prerogative fall on the older adult. More than half of family members believe that EOL treatment decisions ought to be made by the older adult patient, although they still remain the primary decision makers regarding whether the patient accepts life-sustaining treatment. In addition, such family

### KEY WORDS

advance directives, advanced care planning, decision making, do not resuscitate, end of life, long-term care facility

**A**dvance directives (ADs) are legal documents that describe residents' preferences regarding their future treatment at the end of life (EOL). Thus,

**Hsin-Tzu Sophie Lee, PhD**, is assistant professor, Department of Nursing, Tzu Chi University of Science and Technology, Hualien City, Taiwan (ROC).

**Chia-Ling Yang, PhD**, is assistant professor, Mackay Junior College of Medicine, Nursing and Management, Taipei City, Taiwan (ROC).

**Ting-Ru Chen, PhD**, is associate professor, Department of Nursing, Chang Gung University of Science and Technology, Taoyuan City, Taiwan (ROC).

**Sei-Ven Leu, PhD**, Department of Computer Center, Tzu Chi University, Hualien City, Taiwan (ROC).

**Wen-Yu Hu, PhD**, is professor, Department of Nursing, National Taiwan University, Taipei City, Taiwan (ROC).

Address correspondence to Wen-Yu Hu, PhD, Department of Nursing, National Taiwan University, No. 1, Sector 1, Jen-Ai Rd, Zhong Zheng District, Taipei City 10048, Taiwan (ROC) (2011e3188@gmail.com).

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Lee, Ting-Ru Chen, Chia-Ling Yang, Sei-Ven Leu, and Wen-Yu Hu. *Manuscript preparation:* Hsin-Tzu Sophie Lee, Chia-Ling Yang, Ting-Ru Chen, Sei-Ven Leu, and Wen-Yu Hu.

### ORCID IDs:

Hsin-Tzu S. Lee: <https://orcid.org/0000-0002-6916-7066>

Chia-Ling Yang: <https://orcid.org/0000-0001-5086-3558>

Ting-Ru Chen: <https://orcid.org/0000-0002-1548-0938>

Sei-Ven Leu: <https://orcid.org/0000-0003-4687-1277>

Wen-Yu Hu: <https://orcid.org/0000-0001-5244-2458>

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members, despite wishing to know what the older adult's preferences are, find it difficult to enquire about their preferences and expect the health care staff to ask the older adult patients on their behalf.<sup>9</sup> Furthermore, according to Tseng et al<sup>10</sup> (2017), relatives of nursing home residents (n = 213) were highly willing to sign an AD (77%) but very few actually did (9%). Thus, the purpose of this study was to understand the experiences of the family members of residents of a nursing home when signing AD documents in the context of Chinese culture.

## METHODS

### Design

This qualitative study adopted a deductive and descriptive design and a 32-item checklist<sup>11</sup> as per the Consolidated Criteria for Reporting Qualitative Research.

### Setting and Participants

This study was conducted at a nursing home in Taiwan, and purposive sampling was used to recruit interviewees. In the initial stage of the study, 23 relatives of older adult residents (14 relatives of conscious residents and 9 relatives of unconscious residents who were in a persistent vegetative state) indicated their willingness to participate in the study. However, 2 relatives of a conscious resident and 1 relative of an unconscious resident withdrew from the study because the resident transferred to another hospital because of health concerns (n = 2) and 1 relative (n = 1) became unwilling to continue participating in the study. Thus, this study group contained 12 and 8 relatives of conscious and unconscious residents, respectively.

## DATA COLLECTION

Before this study began, the first author worked 2 days per week for 3 months alongside a staff nurse at the nursing home to provide care to residents and converse with the family members. After acquiring a general understanding of the concerns that families of older residents had regarding signing ADs, the first author developed the interview guidelines and discussed them with the fifth author before conducting face-to-face interviews. Formal interviews were conducted in the nursing home, with all interviews being conducted by the first author in Mandarin Chinese or Taiwanese. Each participant received an in-depth, face-to-face interview lasting 30 to 40 minutes with open-ended standard questions (Table 1). After interviewing residents and their relatives, the researchers immediately listened to the audio recordings of the interview, transcribed them to a personal computer, and completed the data analysis within the week. Researchers identified no new themes after they analyzed the data of the 17th relative. However, because 2 relatives of conscious residents and 1 relative

**TABLE 1** Interview Guide

1. Why does the resident live here? How do you feel about them living here?
2. How many chronic diseases does the resident have? Can you tell me more about their present health condition?
3. What is your opinion about the treatment that the resident is presently receiving for these diseases? Are you satisfied with the treatment or management? Why?
4. What is your opinion on filial piety?
5. What do you think about the relationship between yourself and the resident? Who is the closest to the resident? Why?
6. If the condition of the resident becomes serious, what type of care or treatment would you want them to have?
7. What are your family members' opinions about treatment related to end-of-life care for the resident? Have you discussed these issues with the resident?
8. If the resident tells your family that he/she wants to sign his/her own ADs, how would you feel about that?
9. What are your opinions about signing the do-not-resuscitate documents for the resident?
10. In what type of situation would you or your family sign the do not resuscitate documents in advance for the resident?
<i>Abbreviation: ADs, advance directives.</i>

of an unconscious resident (the 18th-20th participants) still indicated a strong willingness to participate in this study, the research team decided to continue interviewing them. No new themes emerged after these data were analyzed, which confirmed that the data were saturated and could be finalized.

## DATA ANALYSIS

A qualitative, inductive content analysis method was used per the guidelines specified by Mojtaba et al<sup>12</sup> and Elo and Kyngas.<sup>13</sup> The transcribed interview content, field notes from visits with each participant, and reflection logs were analyzed as follows: (1) the interview transcripts, field notes, and reflection logs for each participant were recorded in writing and read numerous times by the first author to understand the content. (2) After statements and response units were identified, constellations of words, phrases, and sentences with the same meaning were grouped into meaningful units by the first, second, and third authors, followed by a discussion with and revision by the fifth author. These condensed meaning units were compared and organized into subthemes based on their similarities and differences. These subthemes were subsequently presented or explained to all participants and



revised according to their feedback. (3) The revised sub-themes were extracted from the remaining reviews and allocated into themes. No new themes emerged at this step, and data saturation was achieved before the analysis of the final interview. (4) A potential set of meaning units, subthemes, and themes were reviewed separately by each researcher to verify the validity of the findings and conclusions. Finally, after discussion, all the authors arrived at a consensus regarding the potential set of meaning units, condensed meaning units, subthemes, and themes.

## ETHICAL CONSIDERATIONS

This study was approved by the Medical Foundation Research Ethics Committee in the hospital. Statements regarding consent to participate under the “Ethics, Consent, and Permissions” heading and another under the “Consent to Publish” heading were signed, confirming that the author obtained consent from the participants to publish data and report individual patient data.

## RESULTS

### Demographic and Clinical Characteristics

Twelve participants were family members of conscious residents (code-named A to L) who were between 28 and 72 years old (mean age, 55.5 years; 4 men and 8 women); 8 participants were family members of unconscious residents (code-named uA to uH) who were between 44 and 67 years old (mean age, 52.8 years; 6 men and 2 women). Among the 20 participants, 17 had a college degree, and 3 had no higher education level than elementary school. The participants were the child or grandchild ( $n = 15$ , 75%), child-in-law ( $n = 2$ , 10%), or siblings ( $n = 3$ , 15%) of an older adult at the facility (Table 2).

### Themes

The content analysis revealed 4 themes indicated by family members of older residents concerning the refusal to sign ADs: (1) resident decision, (2) group decision, (3) not entitled to decide, and (4) random decision (Table 3).

#### Theme 1: Resident Decision

Among family members of residents with clear consciousness, 6 mentioned that they were unable to sign because they must “respect the resident's prerogative to sign” and feared that “it'd be regarded as unfilial or inappropriate conduct.” Participants stated the following:

It feels quite unfilial to me to sign beforehand... it should be the case that he first shows the willingness to sign and that he himself should sign this before it's signed by the relative! I'll definitely wait to sign until after my father does it himself. (A)

I'll definitely respect her will... if she signs first or plans to sign.... I will make the arrangement about end of life care for her according to her will. (A-D, I)

#### Theme 2: Group Decision

Five family members of residents with clear consciousness stated that important actions such as signing an AD should be conducted after the family decides as a group. They also felt that there was “no need to sign (an AD) as a decision has already been made in the family.” All relatives of residents without clear consciousness said that signing the resident's do-not-resuscitate (DNR) order in advance was a family matter and that everyone should be involved. Nonetheless, the interviewed relatives also felt that they need not sign a DNR order in advance because “the family members have already made a decision” and “the family has reached an unspoken consensus to let the resident have a good death.” The participants stated the following:

It's not up to me to decide whether to sign or not. I could only tell you that we have discussed among all siblings that in case of anything, mum would get hospice care instead of emergency rescue... we have got a common understanding and are in general agreement. It'd be the same, whether we sign or not... so why sign in advance then? (G)

We're thinking of letting him go smoothly if he is unwell. There's no need for him to deliberately sign it. He's already at this age... ah, because everyone thinks the same, so no one has ever thought about signing anything. (uC)

#### Theme 3: Not Entitled to Decide

Among family members of residents with clear consciousness, 2 said that the most challenging part of signing ADs was that “because the daughter-in-law or married daughter is not a major decision maker, so it would be useless even if whichever signed.” Some relatives of unconscious residents also said that they were unable to sign on behalf of the residents because they “were not the key decision-maker and did not want to be the signatory.” The participants stated the following.

With respect to signing... I'm just the daughter-in-law... it would still be necessary to discuss it with my mother-in-law's children... otherwise, I'd be the signatory... they'd ask why I did not save her and say it's me who killed her... my mother-in-law also has siblings. (uB)

#### Theme 4: Random Decision

Among family members of residents with clear consciousness, 4 mentioned that because both the resident's health condition and the state of the art in medical technology were ever changing, it was “not the right moment” to sign an AD. They felt that asking the relatives to sign an AD



**TABLE 2** Characteristics of Participants (Family Members of Conscious and Unconscious Residents)

Characteristics		Residents' Families (N = 12, A-J)	Unconscious Resident' Family (N = 8, uA-uH)	Total
		n (%)	n (%)	
Sex	Male	4 (33)	6 (75)	10 (50)
	Female	8 (67)	2 (25)	10 (50)
Age, y	20–29	1 (8.3)	0 (0)	1 (5)
	30–39	1 (8.3)	1 (12.5)	2 (10)
	40–49	1 (8.3)	2 (25)	3 (15)
	50–59	2 (17)	3 (37.5)	5 (25)
	60–69	6 (50)	2 (25)	8 (40)
	70–79	1 (8.3)		1 (5)
	80–89			
	>90			
Education	College	10 (83)	7 (88)	17 (85)
	Elementary school	2 (17)	1 (12)	3 (15)
	Illiterate	0 (0)	0 (0)	0 (0)
Relationship	Child (son/daughter/grandchild)	10 (83)	5 (63)	15 (75)
	Child-in-law (son-in-law/daughter-in-law)	0 (0)	2 (25)	2 (10)
	Siblings (brother/sister)	2 (17)	1 (12)	3 (15)

would “go against what they want” or “lead to their abandonment.” Relatives of residents without clear consciousness considered the decision to sign DNR to be “random” because they believed that, although “it was not the right time to sign,” they had long been prepared to “let nature would take its course” by letting the resident pass away; thus, they felt no need to sign a DNR. The participants stated the following:

Whether to sign these documents should only be decided following discussion when something has happened. Every older individual's family situation differs, and we cannot just sign in advance on some presumption that this or that would happen to them...it'd go against what they want. (G)

Health care in the future will definitely be better. After all, how do you know what it is going to look like in the future if you have not been there? It's like in a hospital where many older individuals signed to give up emergency rescue, which was equal to waiting for death, doctors and

nurses just stopped attending to them...and no treatment was given when someone was clearly suffering from severe breathing difficulty. That's exactly what scares me. (F)

It's not yet the moment to sign. She's got many chronic conditions, but she's generally well. When her condition gets worse...we'd sign and let her depart peacefully.... (uC)

**DISCUSSION**

The primary problem faced by the participants when signing an AD was them deferring the decision to sign others.<sup>2,3</sup> Specifically, family members of residents with clear consciousness wished to return the decision-making prerogative back to the resident. However, because death is considered a taboo subject among ethnically Chinese people, no one was willing to broach the topic of EOL care with the resident.<sup>1,4,5</sup> Thus, every family member waited for every other family member to initiate the conversation with the resident, which meant that no AD was signed in



**TABLE 3** Issues Encountered by Relatives When Signing AD Documents for Residents

Theme	Subtheme	Category
1. Resident decision	1.1 Respect for the resident's willingness to sign	1.1.1 Relatives do not dare to sign before the resident
		1.1.2 Relatives will only sign after the resident does
	1.2 Signing by relatives first is deemed to be unfilial or inappropriate	1.2.1 Signing before the resident is unfilial
		1.2.2 It would appear inappropriate to others outside the family
2. Group decision	2.1 Decision-making prerogative falls on the family	2.1.1 It must be decided by the whole family
		2.1.2 Family members have already decided that AD documents do not have to be signed in advance
		2.1.3 Families have already achieved an unspoken consensus to let the resident die a good death
3. Not entitled to decide	3.1 Willing to help but unable to	3.1.1 Not the primary decision maker; useless to sign anyway
		3.1.2 Unwilling to be the "signatory"
4. Random decision	4.1 Not the right moment	4.1.1 Not knowing how much longer the resident will live
		4.1.2 Decision on signing will be discussed when a specific stage in disease progression is reached
		4.1.3 Not the right moment to sign
	4.2 Imposition	4.2.1 Unable to sign based on assumptions made at this moment
		4.2.2 Cannot be treated in a manner similar to that of signing in advance
	4.3 Fear that the resident would be abandoned once the documents are signed	4.3.1 Health care will become more advanced in the future
		4.3.2 Preventive measures should be put in place before anything happens; it is not enough to only think about measures taken for elderly family members at the time of their death

Abbreviation: AD, advance directive.

the end and the resident was placed on the default treatment option of prolonging their life. The findings of this study accord with those of Chen et al,<sup>9</sup> which indicated that most family members wished to return the prerogative to decide EOL care to the older adult but ended up deferring conversations regarding EOL because of Chinese cultural taboos surrounding death. Nonetheless, this finding suggests that an increasingly Westernized and prosperous Taiwanese society is shifting toward recognizing that the right to choose lies with the individual and not his/her family.<sup>9,14,15</sup>

Moreover, the participants felt that it was not the place of any one family member to sign an AD and that the decision to sign should be made collectively. According to Cheung et al<sup>5</sup> and Gu et al,<sup>7</sup> in Chinese culture, critical health care decisions on behalf of a family member are made by the family as a group. Furthermore, some

participants in this study held an insufficiently insider or senior status in the family, being a daughter who had already married (and were thus considered to be a partial outsider, having married out) or a daughter-in-law. This finding supports the findings of previous studies that power differentials within the family—with respect to financial capacity, education level, or sex (which is compounded by the patriarchal nature of traditional Chinese culture)—affect EOL care planning.<sup>8</sup>

The findings of this study also revealed some aspects of EOL care or signing an AD that have not been uncovered in the literature.<sup>5,10,14</sup> The participants revealed the following issues surrounding the signing of ADs. The first was a fear that the older adult resident would be abandoned by the health providers if an AD was signed. The second was a belief that medical advances can render untreatable diseases today treatable, making an AD redundant. The



third was a concern (based on observations of other patients treated similarly) that signing a DNR would lead to clinicians not treating the patient when the patient exhibits signs of discomfort because of breathing difficulties at their final moments, leaving them to die in pain. Therefore, relatives preferred to either sign an AD when the older adult is on the verge of death or make a random decision. The fourth was one faced by relatives of residents without clear consciousness; they thought that the resident was generally healthy, despite being in a persistent vegetative state, and they opted to let nature take its course and to wait for the right moment to sign an AD.

The main reason behind decision delays was the difficulty in determining the timing at which each stage of a terminal illness unfolds for the older adult residents. This resulted in uncertainty regarding the right time to broach the topic of EOL care or signing an AD.<sup>4,14,16</sup> When implementing advanced care planning at a facility, health care staff should reinforce the idea to relatives that death at old age is mostly unexpected or caused by acute infections; the rapidity at which an older adult patient's condition can deteriorate means that relatives need to act quickly to arrive at a decision on EOL care lest the patient be automatically given emergency rescue and miss the opportunity to have a good death.

## LIMITATIONS

This study had several limitations. The sample of this study was not representative of the population because our participants were associated with a single long-term care facility and because it only comprised Hokkien Taiwanese but not Hakka Taiwanese or indigenous Taiwanese people. Second, because our sample was Hokkien Taiwanese, a cross-cultural comparison could not be conducted. Future studies can use a more representative sample or conduct cross-cultural comparisons.

## CONCLUSION

Westernization and increasing economic prosperity have led the decision-making prerogative on EOL matters to fall on the older adult rather than to the family. However, because death is considered taboo among ethnic Chinese, owing to cultural influences from Confucianism, Buddhism, and Taoism, people tend to shy away from discussing matters of death with older adults.<sup>2</sup> When promoting advanced care planning at long-term care facilities, health care staff may serve as the mediator and pass on the residents' views regarding their EOL care to their family members after having separate conversations with each party to increase the chance of residents making independent decisions. When necessary, physicians from the hospice care team may visit

the facility and explain hospice palliative care modes to residents and their relatives separately to ensure that an agreeable decision regarding the modes and objectives of EOL care is reached and that such a decision respects the right of the patient to choose.

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