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Patient–Family Concordance in End-of-Life Decision-Making Preferences Among Terminally Ill Older Adults: A Cross-Sectional Study

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Research Article

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Abstract

Background

Family members frequently participate in end-of-life (EOL) decision-making for terminally ill older adults; however, patients' preferences may not always be accurately understood or represented by family caregivers. Limited concordance between patients and family members may result in treatment decisions that are inconsistent with patients' wishes.

Objective

To examine the concordance of end-of-life decision-making preferences between terminally ill older patients and their family members.

Methods

A cross-sectional survey was conducted between October 2022 and November 2023 at a tertiary teaching hospital in Sichuan Province, China. A total of 505 dyads of hospitalized terminally ill older patients and their family members were recruited using convenience sampling. Data were collected using a demographic questionnaire and a structured survey assessing preferences regarding life-sustaining treatment, preferred place of death, and end-of-life decision-makers.

Results

Concordance regarding life-sustaining treatment preferences ranged from poor to moderate, with kappa coefficients ranging from 0.308 to 0.566. Agreement was highest for tracheotomy preferences and lowest for intravenous blood transfusion preferences. Moderate concordance was observed for preferred place of death ($\kappa = 0.504$) and preferred end-of-life decision-maker ($\kappa = 0.468$). Notably, relatively few patients identified themselves as the preferred final decision-maker for their own end-of-life care.

Conclusion

Substantial discrepancies existed between terminally ill older patients and their family members regarding end-of-life treatment preferences and decision-making roles. Family members may not consistently represent patients' wishes, particularly in family-centered cultural contexts. Promoting advance care planning, shared decision-making, and early patient–family communication may help improve patient-centered end-of-life care for older adults.

Introduction

End-of-life (EOL) decision-making preferences may involve decisions regarding resuscitation and life-sustaining treatment [1–3], preferred place of death [4], and treatment decision-making roles [5, 6]. However, many seriously ill patients have limited opportunities to communicate their goals, values, and EOL care preferences before losing decision-making capacity, and family members or other surrogates are often required to make treatment decisions on their behalf [7, 8]. In China, family members frequently play a central role in medical decision-making, particularly for older patients, and often act as surrogate decision-makers in serious illness and end-of-life care contexts [9, 10]. Previous studies have reported patient–family discrepancies in EOL care preferences, including preferences regarding life-sustaining treatments, preferred place of death, and other care goals [5, 11–13]. Such discrepancies may contribute to unwanted aggressive treatments, unmet EOL care needs, and reduced quality of dying. With rapid population aging in China, EOL decision-making among older adults has become an increasingly important clinical and public health issue. By the end of 2023, China had nearly 297 million people aged 60 years or older, accounting for 21.1% of the total population; people aged 65 years or older reached 216.76 million, accounting for 15.4% [14]. Despite the growing need for patient-centered EOL care, limited research has specifically examined the concordance between terminally ill older patients and their family members regarding EOL decision-making preferences in mainland China.

Materials and methods

Study Design and Participants

This cross-sectional study recruited hospitalized terminally ill older patients and their family members from a large tertiary teaching hospital in Sichuan Province, China, between October 2022 and November 2023. Convenience sampling was used. Patients were eligible if they met the following criteria: (1) aged 60 years or older; (2) diagnosed with a terminal illness, including heart failure, respiratory failure, liver failure, kidney failure, metastatic cancer, or other advanced life-limiting conditions; (3) had an estimated life expectancy of 12 months or less, as determined by two physicians, including the attending physician, using the Surprise Question approach[15]; and (4) were able to communicate and provide informed consent. Patients were excluded if they had unstable vital signs, severe acute illness that precluded participation, cognitive impairment, or a diagnosed mental disorder. Family members were eligible if they met the following criteria: (1) aged 18 years or older; (2) involved in the patient's medical decision-making; (3) able to communicate and complete the questionnaire independently or with assistance in person, by telephone, or via WeChat; and (4) provided informed consent. Family members were excluded if they had cognitive impairment or a diagnosed mental disorder. This study was approved by the Biomedical Ethics Committee of West China Hospital, Sichuan University.

Measures

Demographic questionnaire: Demographic information was collected using researcher-designed questionnaires for patients and family members. The patient questionnaire included age, sex, ethnicity, educational level, religious belief, marital status, number of children, primary caregiver, and medical insurance status. The family member questionnaire included age, sex, ethnicity, educational level, religious belief, occupation, marital status, relationship with the patient, monthly household income, and perceived medical financial burden.

End-of-life decision-making preference survey: The end-of-life decision-making preference survey was adapted from previous patient–family concordance studies on EOL care preferences, including the survey used by Tang et al. to assess goals of EOL care and preferences for life-sustaining treatments [16]. The patient version included three domains: preferences for life-sustaining treatment, preferred place of death, and preferred end-of-life decision-maker.

Preferences for life-sustaining treatment were assessed using seven treatment options: cardiopulmonary resuscitation, tracheotomy, mechanical ventilation, blood transfusion, hemodialysis, nasogastric feeding, and pharmacological resuscitation. For each treatment option, patients were asked whether they would prefer to receive the treatment if their condition deteriorated or if they became unconscious. Response options were "yes" and "no."

Preferred place of death was assessed by asking where patients would prefer to spend the final stage of life. Response options were "hospital," "home," and "other." Preferred end-of-life decision-maker was assessed by asking who patients would prefer to make final treatment decisions on their behalf. Response options were "patient," "family member," "healthcare provider," and "other."

The family member version used parallel items with wording adapted to assess family members' perceptions of the patient's preferences. A pilot survey was conducted with 30 dyads of terminally ill older patients and their family members. The Cronbach's alpha coefficients were 0.810 for the patient version and 0.747 for the family member version.

Data collection

Before data collection, the research team introduced the study purpose, eligibility criteria, and data collection procedures to department managers to facilitate participant identification and recruitment. Eligible patients and their family members were then approached by trained investigators. After written informed consent was obtained, patients completed the patient

version of the questionnaire, and family members completed the family member version independently. For participants with limited reading ability or visual impairment, trained investigators assisted by reading each item aloud and recording the participant's response without interpretation or prompting. All investigators had received training in comprehensive geriatric assessment. Completed questionnaires were reviewed onsite for missing or inconsistent responses. A total of 580 patient–family dyads were approached. Of these, 542 dyads returned questionnaires, yielding a response rate of 93.4%. After excluding incomplete or invalid questionnaires, 505 dyads were included in the final analysis, corresponding to a valid response rate of 87.1%.

Statistical Analysis

Data were analyzed using IBM SPSS Statistics version 22.0. Continuous variables with normal or approximately normal distributions were summarized as means and standard deviations. Categorical variables were summarized as frequencies and percentages. Cohen's kappa statistics were used to examine concordance between terminally ill older patients and their family members regarding preferences for life-sustaining treatments, preferred place of death, and preferred end-of-life decision-makers. A two-sided P value < .05 was considered statistically significant. Kappa values were interpreted as follows: values < 0.40 indicated poor concordance, values from 0.40 to < 0.75 indicated moderate concordance, and values ≥ 0.75 indicated good concordance [17] .

Results

Characteristics of Terminally Ill Older Patients

A total of 505 terminally ill older patients were included in the analysis, including 320 men and 185 women. Patients ranged in age from 60 to 101 years, with a mean age of 84.08 ± 9.80 years. Most patients were Han Chinese (n = 502), had no religious affiliation (n = 489), were covered by medical insurance (n = 501), and had two or more children (n = 405). A total of 268 patients were married, whereas 237 were unmarried. Regarding educational level, 178 patients had completed primary school or less, 114 had completed middle school, 137 had completed high school or college, and 76 had a bachelor's degree or higher. Primary caregivers included spouses (n = 106), other family members (n = 186), paid caregivers (n = 186), and no caregiver (n = 27). The main disease categories were lung diseases (n = 166), cardiovascular and cerebrovascular diseases (n = 145), malignant tumors (n = 138), gastrointestinal or urinary diseases (n = 35), and other diseases (n = 21).

Table 1
Concordance in Life-Sustaining Treatment Preferences Between Terminally Ill Older Patients and Their Family Members (N = 505)

Item	Family preference	Patient preference [n(n%)]			Concordance rate	Kappa value	χ^2 value	*P-value*
		No	Yes	Total				
Cardiopulmonary resuscitation (CPR)	No	143(28.3)	14(2.8)	157(31.1)	71.5%	0.447	11.214	<0.001
	Yes	130(25.7)	218(43.2)	348(68.9)				
	Total	273(54.1)	232(45.9)	505(100)				
Tracheotomy	No	263(52.1)	27(5.3)	290(57.4)	79.4%	0.566	13.001	<0.001
	Yes	77(15.2)	138(27.3)	215(42.6)				
	Total	340(67.3)	165(32.7)	505(100)				
Mechanical ventilation	No	179(35.4)	16(3.2)	195(38.6)	69.5%	0.424	10.7	<0.001
	Yes	138(27.3)	172(34.1)	310(61.4)				
	Total	317(62.8)	188(37.2)	505(100)				
Intravenous blood transfusion	No	77(15.2)	7(1.4)	84(16.6)	66.7%	0.308	8.956	<0.001
	Yes	161(31.9)	260(51.5)	421(83.4)				
	Total	238(47.1)	267(52.9)	505(100)				
Hemodialysis	No	233(46.1)	26(5.1)	259(51.3)	76.2%	0.521	12.167	<0.001
	Yes	94(18.6)	152(30.1)	246(48.7)				
	Total	327(64.8)	178(35.2)	505(100)				
Nasogastric feeding	No	141(27.9)	14(2.8)	155(30.7)	69.5%	0.416	10.633	<0.001
	Yes	140(27.7)	210(41.6)	350(69.3)				
	Total	281(55.6)	224(44.4)	505(100)				
Pharmacological resuscitation	No	66(13.1)	5(1)	71(14.1)	69.9%	0.322	9.346	<0.001
	Yes	147(29.1)	287(56.8)	434(85.9)				
	Total	213(42.2)	292(57.8)	505(100)				

Concordance in Life-Sustaining Treatment Preferences Between Terminally Ill Older Patients and Their Family Members

As shown in Table 1, the proportions of patient–family dyads in which both parties preferred treatment were 43.2% for cardiopulmonary resuscitation, 27.3% for tracheotomy, 34.1% for mechanical ventilation, 51.5% for intravenous blood transfusion, 30.1% for hemodialysis, 41.6% for nasogastric feeding, and 56.8% for pharmacological resuscitation.

Kappa analysis showed poor-to-moderate concordance between terminally ill older patients and their family members regarding life-sustaining treatment preferences. The kappa coefficients ranged from 0.308 to 0.566, and concordance rates ranged from 66.7% to 79.4%. Concordance was lowest for intravenous blood transfusion and highest for tracheotomy. Poor concordance was observed for intravenous blood transfusion and pharmacological resuscitation, whereas moderate

concordance was observed for cardiopulmonary resuscitation, tracheotomy, mechanical ventilation, hemodialysis, and nasogastric feeding.

Concordance in Preferred Place of Death Between Terminally Ill Older Patients and Their Family Members

As shown in Table 2, among patient–family dyads with concordant preferences, 42.6% preferred hospital as the place of death, 28.3% preferred home, and 1.8% preferred other locations.

Kappa analysis indicated moderate concordance between terminally ill older patients and their family members regarding preferred place of death, with a kappa coefficient of 0.504 and a concordance rate of 72.7%.

Table 2
Concordance in Preferred Place of Death Between Terminally Ill Older Patients and Their Family Members(N = 505)

Family preference	Patient preference [n(n%)]				Concordance rate	Kappa value	χ^2 value	*P-value*
	Hospital	Home	Others	Total				
Hospital	215(42.6)	105(20.8)	6(1.2)	326(64.6)	72.7%	0.504	13.79	<0.001
Home	7(1.4)	143(28.3)	8(1.6)	158(31.3)				
Others	3(0.6)	9(1.8)	9(1.8)	21(4.2)				
Total	225(44.6)	257(50.9)	23(4.6)	505(100)				

Concordance in Preferred End-of-Life Decision-Makers Between Terminally Ill Older Patients and Their Family Members

As shown in Table 3, among patient–family dyads with concordant preferences, 22.2% identified the patient as the preferred final decision-maker for end-of-life treatment, whereas 45.5% identified a family member. In contrast, only 3.2% of dyads identified healthcare providers as the preferred decision-makers, and 0.2% selected other decision-makers.

Kappa analysis showed moderate concordance between terminally ill older patients and their family members regarding preferred end-of-life decision-makers, with a kappa coefficient of 0.468 and a concordance rate of 71.1%.

Table 3
Concordance in Preferred End-of-Life Decision-Makers Between Terminally Ill Older Patients and Their Family Members (N = 505)

Family preference	Patient preference [n(n%)]					Concordance rate	Kappa value	χ^2 value	*P-value*
	Patient	Family members	Healthcare provider(s)	Others	Total				
Patient	112(22.2)	32(6.3)	6(1.2)	0(0)	150(29.7)	71.1%	0.468	13.11	<0.001
Family members	66(13.1)	230(45.5)	18(3.6)	3(0.6)	317(62.8)				
Healthcare provider(s)	5(1)	12(2.4)	16(3.2)	0(0)	33(6.5)				
Others	1(0.2)	2(0.4)	1(0.2)	1(0.2)	5(1)				
Total	184(36.4)	276(54.7)	41(8.1)	4(0.8)	505(100)				

Discussion

Concordance Between Terminally Ill Older Patients and Their Families Regarding Life-Sustaining Treatment Preferences Was Limited

As shown in Table 1, the present study demonstrated poor-to-moderate concordance between terminally ill older patients and their family members regarding preferences for life-sustaining treatments, with kappa coefficients ranging from 0.308 to 0.566. These findings suggest that family members may not consistently and accurately represent patients' treatment preferences at the end of life. Concordance varied across different treatment types. Agreement was relatively higher for tracheotomy and hemodialysis, whereas lower concordance was observed for blood transfusion and pharmacological resuscitation. One possible explanation is that highly invasive procedures are often perceived as representing severe illness and substantial physical burden, making patients and family members more likely to engage in explicit discussions regarding these interventions. In contrast, treatments such as blood transfusion or pharmacological resuscitation may be viewed as routine supportive measures, resulting in less clearly communicated preferences.

These findings are broadly consistent with previous studies conducted in Chinese and other Asian populations, which also reported patient–family discrepancies in EOL treatment preferences [5, 11, 12, 18]. However, the degree of concordance observed in this study differed somewhat from earlier reports. Differences in response options across studies may partly explain variations in observed concordance levels. For example, some previous studies included an additional "uncertain" response category, whereas the present study adopted dichotomous response options ("yes/no") [5, 16].

Notably, the refusal rate for cardiopulmonary resuscitation in this study was higher than that reported in previous studies involving younger patients with advanced cancer [2].This difference may partly reflect age-related variations in attitudes toward end-of-life care. Older adults may have greater acceptance of disease progression and mortality after prolonged experiences with chronic illness, functional decline, and repeated healthcare encounters. In contrast, younger patients and their family members may be more inclined to pursue aggressive life-prolonging treatments because of stronger expectations for survival and recovery.

Nevertheless, the findings of this study indicate that substantial gaps remain between older patients' preferences and family members' understanding of those preferences. In the Chinese cultural context, end-of-life decision-making is often family-centered, and discussions about death are frequently avoided [9, 10]. As a result, patients may have limited opportunities to explicitly communicate their wishes regarding life-sustaining treatments. These findings highlight the importance of early and ongoing family communication about end-of-life care preferences. Healthcare professionals should facilitate family discussions and encourage older patients to express their values and treatment priorities. Promoting advance care planning may further support shared decision-making and improve alignment between patients' preferences and family members' decisions [7].

Moderate Concordance in Preferred Place of Death Between Older Patients and Their Families

As shown in Table 2, concordance between terminally ill older patients and their family members regarding preferred place of death was moderate, with a kappa coefficient of 0.504 and a concordance rate of 72.7%. Hospital was the most commonly preferred place of death among patient–family dyads with concordant preferences. These findings are generally consistent with previous studies conducted in Asian populations [13]. However, unlike the study by Tang et al. [13], in which home was the most preferred place of death, hospital death was more frequently preferred in the present study. Previous studies have suggested that dying at home may be associated with better quality of dying among terminally ill patients [19].

The differences observed between the present study and previous Taiwanese studies may partly reflect variations in the development and accessibility of palliative care services between mainland China and Taiwan. In mainland China, hospice and palliative care services have developed rapidly in recent years but still face challenges in service accessibility and

continuity, particularly for home-based care [20]. As patients approach the terminal stage of illness, symptom management and medical care needs may become increasingly complex, leading patients and family members to rely more heavily on hospital-based care. In contrast, Taiwan has established a more comprehensive palliative care system, including community- and home-based services, which may increase patients' confidence in receiving end-of-life care outside the hospital setting [13].

In addition, cultural and family-related factors may also influence preferences regarding place of death. In Chinese society, family members often play a central role in caregiving and medical decision-making [9, 10]. Concerns regarding symptom crises, caregiving responsibilities, and emergency management at home may contribute to a preference for hospital-based end-of-life care. These findings suggest that improving the accessibility and continuity of home-based palliative care services may better support patients' end-of-life preferences and reduce the gap between preferred and actual place of death. Healthcare professionals should also provide greater support and education for family caregivers to improve their preparedness and confidence in home-based end-of-life care.

Limited Patient Autonomy in End-of-Life Decision-Making

As shown in Table 3, concordance regarding the preferred decision-maker for end-of-life treatment between terminally ill older patients and their family members was moderate, with a kappa coefficient of 0.468 and a concordance rate of 71.1%. Notably, only 22.2% of patient–family dyads with concordant preferences identified the patient as the preferred final decision-maker for end-of-life treatment. This finding is comparable to previous studies reporting limited patient-led decision-making and substantial family involvement in EOL care preferences and decisions [5, 7].

Several factors may contribute to the limited preference for patient autonomy observed in this study. In the Chinese cultural context, medical decision-making is often family-oriented, and family members commonly assume major responsibility for treatment decisions involving seriously ill older adults [9, 10]. Rather than emphasizing individual autonomy alone, EOL decisions are frequently made within the context of family relationships and collective responsibilities. This family-centered approach may partially explain why both patients and family members tended to prefer family-led decision-making in the present study.

In addition, family-mediated disclosure of serious illness remains common in many Chinese clinical contexts and is closely related to family-centered decision-making [9, 10]. Family members may request that prognostic information be withheld from older patients because of concerns regarding emotional distress or loss of hope. As a result, some patients may have limited opportunities to fully understand their condition and participate in EOL decision-making.

These findings highlight the importance of promoting patient participation in EOL communication and decision-making while remaining sensitive to cultural and family contexts. Healthcare professionals should encourage open discussions among patients, family members, and healthcare teams regarding treatment goals and care preferences. Improving communication about serious illness and supporting shared decision-making may help older patients participate more actively in decisions regarding their EOL care [7, 10]. At the same time, patients' preferences regarding the extent of information disclosure and involvement in decision-making should also be respected.

Clinical implications

These findings have important implications for geriatric and palliative care practice. First, healthcare professionals should not assume that family members can accurately represent older patients' EOL preferences, even when family members are closely involved in care. Routine assessment of patient–family concordance may help identify discrepancies before critical treatment decisions arise. Second, structured patient–family communication and advance care planning discussions should be initiated earlier for terminally ill older patients, particularly when life-sustaining treatments, preferred place of death, or surrogate decision-making roles need to be clarified [7]. Third, nurses and other healthcare professionals can play a key role in facilitating communication among patients, family members, and physicians, supporting patient participation while remaining sensitive to family-centered cultural contexts [9, 10].

Strengths and Limitations

This study has several notable strengths. First, the study specifically focused on terminally ill older adults, a population that faces complex and highly sensitive EOL decision-making challenges but remains underrepresented in related research. Second, the dyadic study design enabled direct comparison between patients' preferences and family members' perceptions, providing a more comprehensive understanding of concordance in EOL decision-making. In addition, family members included in this study were directly involved in medical decision-making rather than solely providing daily care, which may have improved the clinical relevance of the findings.

Several limitations should also be acknowledged. First, participants were recruited from a single tertiary hospital in Sichuan Province using convenience sampling, which may limit the generalizability of the findings to other regions, healthcare settings, and community-based older populations. Second, the cross-sectional design only captured preferences at a single time point and did not account for potential changes in EOL preferences over time. Preferences regarding EOL care may evolve as illness progresses or symptom burden changes. Third, stated preferences may not necessarily reflect actual EOL decisions in real clinical situations, particularly when patients experience rapid deterioration or when family members assume greater decision-making responsibility during critical illness.

Future studies could include multicenter longitudinal investigations involving diverse healthcare settings to further examine how EOL preferences change over time and how these preferences influence actual treatment decisions and EOL care outcomes. Further research exploring factors associated with patient–family concordance may also help inform interventions aimed at improving shared decision-making and advance care planning among older adults.

Conclusion

This study identified substantial discrepancies between terminally ill older patients and their family members regarding EOL treatment preferences and preferred decision-makers. Concordance varied across different life-sustaining treatments and was generally only poor to moderate. In particular, patient autonomy in EOL decision-making remained limited, with relatively few patients identified as the preferred final decision-maker for their own care. Moderate concordance was also observed regarding preferred place of death.

These findings highlight the complexity of EOL decision-making among older adults within family-centered cultural contexts. Family members may not always accurately represent patients' preferences, particularly in situations involving complex treatment decisions and serious illness communication. Healthcare professionals should promote earlier and more open discussions regarding EOL care preferences and support greater patient participation in shared decision-making. Strengthening advance care planning and family communication may help improve the alignment between patients' preferences and family members' decisions, thereby facilitating more patient-centered EOL care for older adults.

Declarations

TJ and DW contributed equally.

TJ and DW are joint first authors.

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Authors' contributions

TJ, DW, QC, and QZ contributed to the conception and design of the study. TJ and DW contributed to data acquisition. TJ, DW, and QZ contributed to data analysis. TJ, DW, and QC contributed to data interpretation. QC contributed to drafting the

manuscript and critically revising it for important intellectual content. All authors read and approved the final manuscript. TJ and DW contributed equally to this work and share first authorship.

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Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to privacy and ethical restrictions, but are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

This study was approved by the Biomedical Ethics Committee of West China Hospital, Sichuan University (approval No. 1051 in 2022). All procedures were conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants before data collection.

Consent for publication

Not applicable.

Competing interests

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