

Development and Evaluation of a Questionnaire on the Acceptability of Advance Care Planning for the Families of End-Stage Patients with Chronic Diseases

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To cite this article:

Shen Yongqing, Yang Yanting, Gao Rui, Wang Yongli, Liu Wei et al. (2023). Development and Evaluation of a Questionnaire on the Acceptability of Advance Care Planning for the Families of End-Stage Patients with Chronic Diseases. *Clinical Medicine Research*, 12(6), 103-109. <https://doi.org/10.11648/j.cmr.20231206.11>

Received: September 24, 2023; **Accepted:** October 23, 2023; **Published:** November 29, 2023

Abstract: The objective of this study was to construct and evaluate a questionnaire about the acceptability of advance care planning among the families of end-stage patients with chronic diseases. The reliability and validity of the questionnaire were then evaluated by consulting with 11 experts and testing the questionnaire on 406 family members of patients with end-stage chronic diseases. The overall content validity was 0.96, and the Cronbach's α coefficient of the questionnaire was 0.904. The questionnaire exhibited good reliability and validity, indicating that it can be used as a research tool to evaluate the acceptance of advance care planning among the families of patients with chronic disease.

Keywords: Advance Care Planning, End Stage, Acceptability, Questionnaire, Reliability, Validity

1. Introduction

In recent years, with the aging of China's population, the prevalence of chronic diseases has increased. [1] Chronic disease, also known as non-communicable chronic disease (NCD), is an umbrella term for a class of communicable diseases with complex etiology, insidious onset, and long-duration, protracted illness. End-stage NCD (expected survival less than six months) is often accompanied by a loss of organ function. Most with end-stage NCD face decisions about whether to use life-sustaining technologies, [2] and they may lose the opportunity to express their preferences due to the severity of their condition. In this context, family members often play an important role in medical decision making. [3] Unprepared to face changes in the patient's condition and to make difficult decisions, family members often experience negative emotions such as anxiety, depression, and isolation. [4] Furthermore, families are often unable to accurately

predict patients' end-of-life preferences [5] and may not make decisions based on the patients' wishes; rather, they may make decisions based on what they believe is appropriate for their own end-of-life stage. [6] Thus, the patient's quality of life may be compromised.

Advance care planning (ACP), which includes designating a medical decision agent with clear awareness, can help NCD patients plan, prepare, and express their personal values and future medical goals. Thus, ACP can help relieve the painful symptoms of NCD patients, improve their quality of life, and reduce the decision-making burden among their families along with the associated anxiety and depression. [7, 8]

While ACP is widely recognized in western countries, ACP remains in its infancy in mainland China due to the influence of traditional Chinese culture and society. [9, 10] Due to the dominance of family decision making in China, the patient's family is a key factor in the discussion of ACP. [3] Patient families are critical in decision making related to ACP, and differences in opinion among family members or poor

communication between family members and patients will affect the implementation and outcomes of ACP. [11] Therefore, understanding the acceptance of ACP by family members of patients with end-stage NCD is crucial to promote effective implementation of ACP.

Few ACP studies have focused on the families of patients with end-stage NCD, and no effective measurement tool for ACP acceptance in China currently exists. Therefore, based on previously developed questionnaires and consultation with experts both in China and abroad, we developed an ACP acceptability questionnaire in line with China's national conditions and verified its reliability and validity. The objective was to reveal the status of ACP acceptance among families of patients with end-stage chronic disease in China, encourage timely and effective dialogue, and provide an applicability assessment tool for future ACP interventions for families of patients with end-stage chronic disease.

2. Methods

2.1. Research Objects

From November to December 2019, members of the research group invited 11 experts to evaluate the content of a draft questionnaire. The selection criteria for experts were as follows: (1) bachelor degree or above; (2) working in gerontology, oncology, critical care medicine, emergency medicine, medical ethics, and another related field for over 10 years; (3) knowledge of ACP; (4) holds the title of senior deputy or above for a medical expert or the title of chief nurse or above for a nursing expert; (5) familiar with the Delphi expert consultation method; and (6) willing to cooperate with this study.

We adopted a cross-validation method, and the samples were randomly divided into two groups for exploratory factor analysis and confirmatory factor analysis. For confirmatory factor analysis, the sample size should be 10–20 times the number of items. [12] In this study, 19 items were tested; thus, the sample size was calculated as $20 \times 19 = 380$. Considering an invalid rate of 20%, a total of 460 questionnaires were sent out for verification. From March to July 2020, the family members of patients in the chronic disease wards (departments of cardiology, endocrinology, respiration, oncology, etc.) from five Grade III, Class A hospitals in Hebei Province were selected for investigation. The patient survival time was less than six months according to the clinical experience of professional doctors. The inclusion criteria were as follows: (1) family members or primary caregivers (care time \geq three months) of hospitalized patients with NCD; (2) clear of mind and can read text correctly; (3) age \geq 18 years; and (4) volunteer to participate in this study. People with problems that could cause emotional excitement or other uncomfortable emotions were excluded. This study was approved by the

ethics committee of the college, and all the respondents were informed and volunteered to participate in this study.

2.2. Preparation of the Preliminary Questionnaire

2.2.1. Research Team

The research team was composed of nine members with an average age of 35.33 ± 10.28 years. The team included one professor of medical education, one chief physician, one chief nurse, one statistics expert, and five graduate students. These team members were responsible for the literature review, questionnaire items, expert consultation, and analysis of advice received by the experts.

2.2.2. Questionnaire Dimensions

A total of 53 articles were retrieved from the literature, including 21 in Chinese and 32 in English. In combination with China's national conditions, the development status of ACP in China, and the opinions of the group of experts, "ACP acceptance" was defined as the degree of recognition and adoption of ACP by the families of patients with end-stage NCD. Based on this definition, the questionnaire was initially divided into three dimensions: "feelings about ACP related issues," "attitudes toward ACP," and "behavioral intention to implement ACP."

2.2.3. Construction of Questionnaire Items

To determine the dimensions of the questionnaire, we used a literature review, brainstorming, group discussion, and expert consultation in combination with the interpretation of the three dimensions. A questionnaire item pool was developed to cover the following aspects: personal feelings, service needs, illness notification, life values, and behavior choice. A total of 19 initial items were identified: five categorized as "ACP-related feelings," nine categorized as "attitudes toward ACP," and five categorized as "behavioral intention to implement ACP." All items were intended to be evaluated using a Likert five-point score (1–5 points ranging from 0, "strongly disagree," to 5, "strongly agree").

2.2.4. Delphi Expert Consultation

Eleven experts from Beijing, Guangdong, Hebei, Zhejiang, Shandong, and other provinces were invited to participate in two rounds of consultation on the first draft of the questionnaire. The correlation between each item and relevant content dimensions was evaluated using Likert four-point scoring. The importance of each item was evaluated using Likert five-point scoring. The questionnaire items were adjusted according to the evaluation opinions of the experts, and validity of the questionnaire was evaluated. The experts consulted included six clinical nursing experts, three clinical medical experts, and two medical education experts. The other basic information is shown in Table 1.

Table 1. Characteristics of experts consulted in this study.

Factor	Category	Number of cases	Proportion of experts (%)
Gender	man	1	9.09
	woman	10	90.91

Factor	Category	Number of cases	Proportion of experts (%)
Age	18–35 years	1	9.09
	36–44 years	6	54.55
	45–59 years	4	36.36
Education	undergraduate degree	3	27.27
	master's degree	6	54.55
	doctoral degree or above	2	18.18
Work domain	clinical care	4	36.36
	clinical medicine	5	45.45
	medical education	2	18.18
Occupation	oncology	2	18.18
	emergency medicine	1	9.09
	ICU	4	36.36
	gerontics	3	27.27
	medical ethics	1	9.09
Years of work experience	10–15 years	1	9.09
	16–20 years	5	45.45
	20 years or above	5	45.45
Work title	medium-grade professional title	3	27.27
	associate senior title	5	45.45
	senior title	3	27.27

2.3. Preliminary Investigation

To test the readability and acceptability of the questionnaire, a preliminary survey was conducted on 25 family members of end-stage patients in the chronic disease ward of a Grade III, Class A hospital in Shijiazhuang, Hebei Province. The inclusion and exclusion criteria of the pre-survey population were consistent with those of the formal survey. Analyze the feedback and modify the questionnaire content accordingly. According to the test, the subjects spent the shortest time of 126 s, the longest time of 932 s, the average time of 473.32 ± 231.48 s. The preliminary results suggested that the questionnaire had good readability and acceptability.

2.4. Questionnaire

In this study, the questionnaire was distributed into two forms (online and face to face). Before the investigation, the members of the research team were uniformly trained. The questionnaire data were collected in strict accordance with the accepted standards, and unified guidelines were applied to guide the completion of questionnaires. After receiving the questionnaire, we checked for any missing or unclear items and made corrections are necessary while avoiding investigator bias. The completed questionnaires were reviewed to eliminate any invalid responses, and the data were sorted and coded to ensure the accuracy of the obtained data. The questionnaire consists of four parts: (1) general information, including gender, age, occupation, marital status, relationship with patients, religious beliefs, residence, education level, family monthly income, and patient's medical payment; (2) patient characteristics, including the type of chronic disease, duration of disease, and self-care ability; (3) ACP experiences referring to Hsiung's [13] "Chinese Americans' Previous End-of-life (EOL) Experiences," which asks if you have ever cared for a terminally ill family member, have ever been confused about end-of-life care decisions, and

have discussed end-of-life care decisions with anyone; and (4) the ACP acceptability of the families of patients with end-stage NCD. A total of 460 questionnaires were sent out; 54 questionnaires with a filling time of less than 120 s and a standard deviation of less than 0.5 were excluded, leaving 406 valid questionnaires with an effective response rate of 88.26%.

2.5. Statistical Methods

SPSS 25.0 and AMOS 24.0 were used for statistical analyses. the Kendall harmony coefficient test and χ^2 test were used to describe the degree of coordination among expert opinions. Item analysis, including the critical ratio method and total question correlation method, was used to screen and evaluate the questionnaire items. Validity analysis was conducted based on content validity and structure validity. Content validity was based on the expert validity index (CVI). Structural validity was evaluated through exploratory factor analysis and confirmatory factor analysis. Cronbach's α coefficient was used for reliability analysis, and $P < 0.05$ was considered statistically significant.

3. Results

3.1. Expert Consultation

Eleven experts were invited to participate in two rounds of expert consultation in Delphi, and the response rate for both rounds was 100%. The opinion rates in rounds 1 and 2 were 81.32% and 36.36%, respectively, and the expert authority coefficients were 0.85 and 0.87, respectively. The average coefficient of variation in rounds 1 and 2 were 0.13 and 0.12, respectively, while the coefficients of coordination among the expert opinions were 0.45 and 0.56, respectively. Thus, the results of the consultation were reliable. According to the consultation, item 5 ("If you are a patient, would you like to know the truth about your condition?") was assigned a mean

significance of < 3.5 and a coefficient of variation > 0.25 ; thus, this item was deleted. The experts did not think that item 8 (“You think the current hospital environment can meet the physical and mental needs of patients”) was clear and suggested splitting it into two items (“You think the current hospital environment can meet the physical needs of patients” and “You think the current hospital environment can meet the psychological needs of patients”). The dimensions of

individual items were adjusted. After addressing the first round of expert opinion, the second round of consultation was conducted. In the second round of consultation, the mean value of importance assignment of each item was > 3.5 , the coefficient of variation was < 0.25 , and the full score ratio of each item was > 0.2 . The opinions of the experts were generally consistent, indicating the validity of the final questionnaire items.

Table 2. Questionnaire critical ratio table of the high and low groups ($n = 406$).

Item	Average		Resolution coefficient	Levene variance Equality test		T (CR)	P
	Low group	High group		F	P		
Q1	3.16	3.08	-0.08	12.243	0.743	0.329	0.001
Q2	2.96	2.94	-0.02	27.705	0.939	0.076	0.000
Q3	1.61	3.13	1.52	6.262	0.000	9.910	0.014
Q4	1.45	3.19	1.74	0.573	0.000	11.792	0.451
Q5	1.43	3.08	1.65	0.190	0.000	11.193	0.664
Q6	1.29	3.04	1.75	3.663	0.000	12.516	0.058
Q7	1.73	3.40	1.67	2.527	0.000	10.811	0.115
Q8	3.25	3.19	-0.06	14.785	0.809	0.243	0.000
Q9	1.12	2.87	1.75	29.555	0.000	12.534	0.000
Q10	1.12	2.83	1.71	16.132	0.000	12.303	0.000
Q11	1.75	3.21	1.46	5.285	0.000	9.024	0.024
Q12	1.00	2.83	1.83	65.670	0.000	13.659	0.000
Q13	1.25	2.92	1.67	1.341	0.000	11.230	0.250
Q14	2.98	2.77	-0.21	25.917	0.351	0.939	0.000
Q15	1.57	2.83	1.26	0.772	0.000	6.355	0.382
Q16	1.24	2.90	1.66	1.642	0.000	11.401	0.203
Q17	1.31	3.02	1.71	0.013	0.000	11.626	0.908
Q18	1.31	3.00	1.69	0.659	0.000	11.814	0.419
Q19	1.22	2.88	1.66	5.941	0.000	12.349	0.017

3.2. Survey Results

Revise the questionnaire through critical ratio method and overall correlation method.

3.2.1. Critical Ratio Method

The total score was calculated after the reverse coding of the questionnaire results, and the total scores of the 406 questionnaires were ranked from high to low. The 110 questionnaires with the highest scores were set as the high group (27% of all questionnaires), while the remaining 296 questionnaires were set as the low group (27% of all questionnaires). The differences in each item between the high and low groups were assessed by independent sample T-test, and the T-values of each item were compared. As shown in Table 2, P exceeded 0.05 for four items (Q1, Q2, Q8, and Q14), which do not have the identification degree. Therefore, these four items were deleted, while the other items were retained.

3.2.2. Overall Correlation Method

The correlation between each item of the questionnaire and the total score of the questionnaire was greater than 0.4 with $P < 0.05$, indicating that each item had a certain degree of discrimination. Therefore, the 15 items were retained for subsequent analysis (Table 3).

Table 3. Correlation coefficient between each item and the total score ($n = 406$).

Item	Correlation coefficient	P	Item	Correlation coefficient	P
Q3	0.661	0.000	Q12	0.767	0.000
Q4	0.714	0.000	Q13	0.773	0.000
Q5	0.707	0.000	Q15	0.572	0.000
Q6	0.706	0.000	Q16	0.758	0.000
Q7	0.629	0.000	Q17	0.725	0.000
Q9	0.761	0.000	Q18	0.736	0.000
Q10	0.773	0.000	Q19	0.764	0.000
Q11	0.613	0.000			

3.3. Validity Analysis

3.3.1. Content Validity

Based on the expert consultation results, the content validity index (I-CVI) of each item was 0.82–1.00, and the I-CVIs of “feelings about ACP,” “attitudes about ACP,” and “behavioral intention to implement ACP” were 0.96, 0.97, and 1.00, respectively. The overall content validity of the questionnaire was 0.96.

3.3.2. Construction Validity

Exploratory factor analysis was performed on the data from 203 subjects using SPSS 25.0. Among where, KMO = 0.909, Bartlett’s sphericity test $P < 0.001$, indicating that the sample

was suitable for factor analysis. Factor rotation was performed by principal axis factorization, and the maximum variance method was used to extract the factors whose characteristic roots were greater than 1. Combined with the results of the gravel plot (see Figure 1), the curve tends to flatten after the third factor, so we decided to extract three factors. Delete the item with the common degree < 0.2 , the maximum load < 0.4 ,

the difference between the maximum absolute value and the second load value < 0.1 or the absolute value of both loads > 0.4 . [14] According to the project load table (Table 4), a second factor analysis was performed after removing question Q13 with common degree < 0.2 . The final questionnaire included three factors and 14 items, and the cumulative variance contribution rate reached 62.83%, as shown in Table 5.

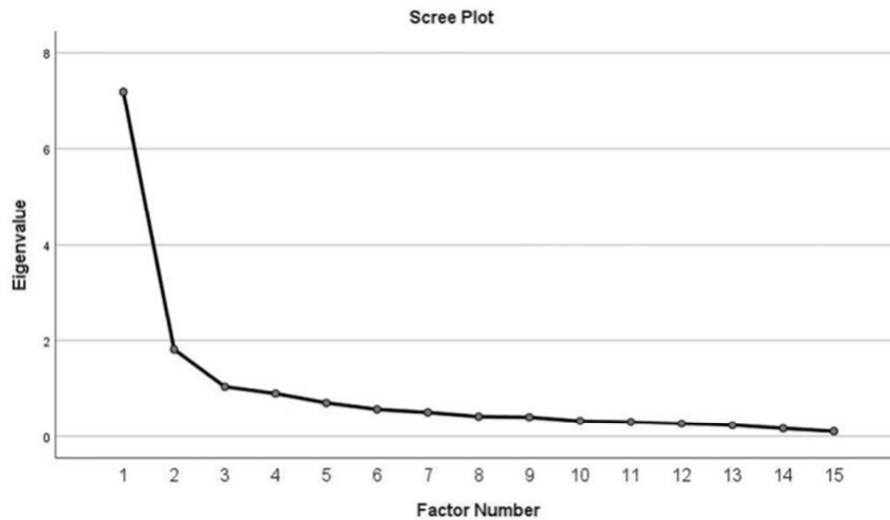


Figure 1. Lithographs of ACP Acceptance Questionnaire.

Table 4. Project load table.

Item	Initial value	Extract	Item	Initial value	Extract
Q3	0.366	0.394	Q12	0.639	0.639
Q4	0.529	0.571	Q13	0.154	0.114
Q5	0.428	0.402	Q15	0.802	0.771
Q6	0.558	0.618	Q16	0.822	0.794
Q7	0.575	0.676	Q17	0.555	0.581
Q9	0.680	0.689	Q18	0.754	0.890
Q10	0.647	0.654	Q19	0.701	0.738
Q11	0.396	0.375			

Table 5. Component matrix after rotation of the items to be tested.

Item		Factor loading			Communality
		1	2	3	
A1	Q3	0.724	0.321	0.256	0.693
A2	Q4	0.721	0.296	0.231	0.660
A3	Q5	0.437	0.354	0.294	0.402
A4	Q6	0.691	0.242	0.342	0.652
A5	Q7	0.469	0.342	0.156	0.361
A6	Q15	0.764	0.192	0.377	0.763
A7	Q16	0.794	0.204	0.338	0.786
B1	Q9	0.273	0.552	0.130	0.396
B2	Q10	0.193	0.746	0.164	0.620
B3	Q11	0.142	0.797	0.140	0.676
B4	Q12	0.310	0.671	0.157	0.571
C1	Q17	0.318	0.149	0.674	0.578
C2	Q18	0.307	0.216	0.871	0.900
C3	Q19	0.333	0.205	0.763	0.735
Eigenvalue		3.682	2.629	2.485	
% of variance		26.297	18.776	17.753	
Cumulative %		26.297	45.073	62.825	

24.0 was used to conduct confirmatory factor analysis on the other half of the data (i.e., the validation data; $n = 203$). The resulting model is shown in Figure 2. The factor loads of all items ranged from 0.54–0.88. The model fitting degree is shown in Table 6. All parameters reached the standard, and the model had a good fitting degree.

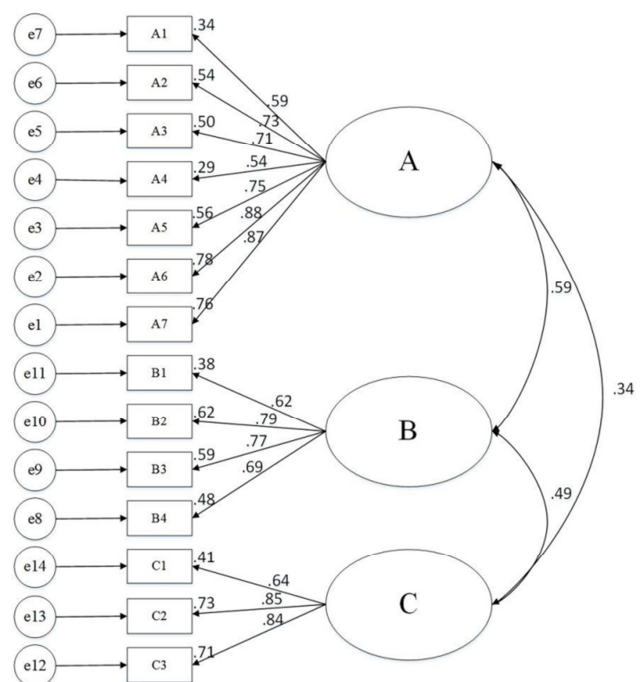


Figure 2. Model diagram of ACP acceptance confirmatory factor analysis.

To further observe the fitting degree of the model, AMOS

Table 6. Model fit.

Fitting index	Tolerance interval	Observed value
χ^2/df	< 3	2.713
GFI	> 0.9	0.916
SRMR	< 0.08	0.063
RMSEA	< 0.08	0.073
IFI	> 0.9	0.921
TLI (NNFI)	> 0.9	0.902
CFI	> 0.9	0.921
NFI	> 0.9	0.904

3.3.3. Reliability Analysis

The Cronbach's α coefficient of the total ACP acceptability questionnaire was 0.904, and the Cronbach's α coefficient of the three dimensions were 0.895, 0.808, and 0.859, indicating that the questionnaire had good internal consistency. [15]

4. Discussion

4.1. Significance of the Questionnaire

To our knowledge, this is the first attempt in China to develop a tool for assessing ACP acceptance among families of patients with end-stage NCD. Our ACP acceptance assessment tool involves three dimensions: ACP attitudes, feelings, and behavioral intentions. In China, family members play an important role in a patient's end-of-life decision-making process. Influenced by the traditional concept of filial piety, family members may choose to conceal the condition from the patient to protect the patient, [16, 17] resulting in the patient being unable to make plans and medical decisions for themselves. However, decision making for patients in advanced life stages is a full of uncertainty, [2] and families bear enormous pressure. Families of some patients with end-stage NCD say that although they know that resuscitation is ineffective, do not want the patient to continue to suffer, and want to opt out of treatment, they still choose resuscitation due to social and familial pressures. [18] Timely assessment of ACP acceptance by families of patients with end-stage NCD is important to alleviate this dilemma and ensure that patients receive care in a manner consistent with their preferences. [19] The exploration of ACP acceptance can help families properly understand ACP, fully understand patients' wishes, and provide a basis for family proxy decision making. Therefore, the development of an ACP acceptance questionnaire for families of patients with end-stage NCD in China is important for improving the quality of life of end-stage patients and reducing the burden of family decision making. This assessment tool can also be combined with the related tools for assessing ACP acceptance among patients to investigate the consistency of ACP acceptance between these two groups. It can also provide a basis for understanding the effectiveness of promoting ACP among patients and family members.

4.2. The Questionnaire Is Scientific and Practical

The questionnaire in this study was prepared based on the concept of acceptability and a literature review. The questionnaire covers the feelings, attitudes, and behavioral

intentions of ACP, ensuring the scientific and practical nature of the questionnaire. Experts in related fields (e.g., hospice care, oncology, gerontology, emergency medicine, critical care medicine, medical ethics, and medical education) evaluated the questionnaire to ensure its validity. In addition, we conducted project analysis, factor analysis, and other methods to revise and screen the items. We then tested the reliability and validity of the questionnaire through a multi-center survey to ensure scientific and rigorous content. The length of the questionnaire is suitable, the questionnaire items are easy to understand, and the questionnaire is convenient for clinical application.

4.3. The Questionnaire Has Good Validity

We employed content validity and construction validity to evaluate the validity and accuracy of the questionnaire. According to the literature, when the number of experts is less than or equal to five, I-CVI should be 1.00. When the number of experts is greater than five, the I-CVI should be ≥ 0.78 . [20] The S-CVI of the questionnaire was calculated as the mean of all I-CVI values; the S-CVI should reach 0.90. [21] The I-CVI values of the items in our questionnaire ranged from 0.82–1.00, and the content index of the questionnaire's three dimensions ("feelings about ACP," "attitudes about ACP," and "behavioral intention to implement ACP") were 0.96, 0.97, and 1.00, respectively. The overall content validity of the questionnaire was good (0.96). Structural validity indicates whether the structure of the questionnaire is consistent with the theoretical framework of the questionnaire. Three common factors were extracted through exploratory factor analysis, and the load values of each item on each factor exceeded 0.4. The cumulative variance contribution rate was 62.83%. The common factor distribution of each item was essentially consistent with the theoretical framework of questionnaire design. Confirmatory factor analysis confirmed good model fitting ($\chi^2/df < 3$). An approximate root mean square error (RMSEA) less than 0.08 indicates good model fitness. In this study, the factor loading of each questionnaire item was 0.54–0.88, and IFI, TLI, CFI, and NFI all reached acceptable statistical standards, indicating that the model was well fitted.

4.4. Questionnaire Reliability

Reliability mainly reflects the accuracy, stability, and consistency of the questionnaire. In this study, we evaluated the reliability of the questionnaire based on internal consistency. In the field of social science, Cronbach's α coefficient is used to estimate the reliability of Likert-scale questionnaires. A coefficient exceeding 0.8 is generally considered to indicate good reliability, while $\alpha > 0.9$ indicates very good reliability. [22] The Cronbach's α coefficient of the ACP acceptance questionnaire developed in this study was 0.904, and the Cronbach's α coefficients of the three dimensions were 0.895, 0.808, and 0.859, indicating good internal consistency. Retest reliability refers to the stability of the results of repeated questionnaire measurement after a period of time. However, since ACP acceptance will change

with the progression of the patient's disease or evolution of the family's perception of ACP, retest reliability was not evaluated in this study.

5. Conclusion

In this study, we developed and tested a questionnaire to assess the acceptance of ACP among the families of patients with end-stage NCD. The questionnaire was prepared in strict accordance with the questionnaire preparation process. A thorough evaluation of the questionnaire revealed good reliability and validity, indicating that the questionnaire can be used in investigations. However, this study has some limitations. Due to the limited research resources, only five Grade III, Class A hospitals located in the same province served as research sites in this study, limiting the representativeness of the samples. In the future, the questionnaire should be verified in a larger region with a larger sample size.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by Humanities and Social Science Research Program of The Ministry of Education of China (18YJAZH074).

Ethics Approval

The study protocol has been approved by the Ethics Committee of Hebei University of Chinese Medicine (YXLL2019047).

Acknowledgments

The authors thank AiMi Academic Services (www.aimieditor.com) for the English language editing and review services.

Conflicts of Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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