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Original Article

Adaptation and validation of the Chinese version of palliative care difficulties scale

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ABSTRACT

Objective: The Palliative Care Difficulties Scale (PCDS) is the most popular tool in developed countries for the assessment of difficulties perceived by clinical professionals in palliative care practice. This study aimed to culturally adapt the PCDS into a Chinese version and validate the psychometric properties of the adapted Chinese version of the PCDS.

Methods: The study was carried out in two major phases: (1) translation and cultural adaption of the PCDS into a Chinese version according to the corresponding guidelines, and (2) evaluation of the psychometric properties of the adapted Chinese version of the PCDS by consulting experts and performing a cross-sectional survey among 284 nurses and physicians. Floor and ceiling effects were estimated by the percentage of participants obtaining the lowest or highest possible scores. Internal consistency reliability was assessed using the Cronbach's α coefficient. Test–retest reliability was evaluated by the intra-class correlation coefficient (ICC). Content validity was evaluated by the content validity index (CVI). Construct validity was calculated by applying the confirmatory factor analysis (CFA).

Results: The PCDS was translated and culturally adapted into a Chinese version. Neither floor nor ceiling effects were observed. The scale-level Cronbach's α coefficient was 0.94 with each dimension ranging from 0.84 to 0.92. The scale-level ICC was 0.66 with each dimension ranging from 0.41 to 0.65. Both the item-level and scale-level CVIs were equal to 1. The CFA verified the five-factor structure of the original PCDS with factor loadings for each item ranging from 0.62 to 0.96.

Conclusions: The Chinese version of the PCDS showed satisfactory psychometric properties. It is a valid and reliable tool for the assessment of difficulties perceived by clinical staff in palliative care practice.

Introduction

With the accelerated population aging and an increase in the number of people with advanced chronic illness, the demand for palliative care services is increasing rapidly.[1,2] Palliative care has been more and more prevalent in developed countries.[3,4] However, palliative care is still at the initial stage in many developing countries as various difficulties and challenges exist.[5–7] For instance, palliative care has been challenging in China owing to a large aging population while insufficient infrastructure and facilities for palliative care.[7,8] According to the 2015 quality of death index, China ranked 71st out of 80 countries, which was way behind many countries,[9] reflecting the limited availability and poor quality of palliative care in China. We recognize that many barriers exist in the development of palliative care, and there is still a long way to go to establish a high-quality palliative care system in China.[8] Identifying the barriers and difficulties in palliative care practice would be helpful in improving palliative care in China as new measurements could be taken accordingly.

Nevertheless, research about the existing difficulties in palliative care practice is very limited. To date, several studies tried to adopt a qualitative design to investigate the challenges experienced by clinical staff during palliative care practice.[10,11] However, these studies only focused on a small group of clinical staff in a particular region, and thus, the conclusion may not be generalized in other regions. To our best knowledge, there are no relevant studies that cover larger regions in developing countries and reveal the difficulties encountered by clinical staff in palliative care practice, mainly due to the lack of an appropriate and valid tool that could be applied locally.

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The Palliative care difficulties scale (PCDS), developed by Nakazawa et al. and presented in both Japanese and English, is a popular tool for palliative care practice in developed countries.[12–14] It has been translated into a Spanish version as well.[15] The PCDS covers a wide range of aspects related to palliative care practice and comprises five domains: communication among multidisciplinary teams, communication with patients and families, expert support, alleviation of symptoms, and community collaboration. A Likert five-point scale is used to assess the frequency of problems in clinical practice, and a higher value indicates a higher level of perceived difficulties. The exploratory factor analysis of the original tool supports a five-factor structure, and Cronbach's α coefficients in each domain ranged from 0.85 to 0.93.[12] The PCDS can be used as an objective measure to identify the difficulties experienced by medical professionals in palliative care practice and to determine what aspects need to be improved. The conclusion will be helpful in developing new strategies to support and enhance the current palliative care service system. Moreover, the conclusion will also be helpful in evaluating the efficacy of the supporting measures received by medical professionals and ultimately improving the quality of palliative care received by patients and their families.

Considering its satisfactory psychometric properties and practical value, the PCDS has shown great potential to be applied in Chinese palliative care practice. However, palliative care relates to the topic of death, which might be perceived quite differently in different cultures and is a very sensitive topic in traditional Chinese culture.[10] Thus, it is necessary to implement a cross-cultural adaption before the PCDS could be applied in palliative care practice in another country such as China. Therefore, this study aimed to translate and culturally adapt the PCDS into a Chinese version and evaluate the reliability and validity of the Chinese version of the PCDS.

Methods

The study was carried out in two major phases: (1) translation and cultural adaption, and (2) psychometric evaluation. Fig. 1 presents the flow diagram of the whole study.

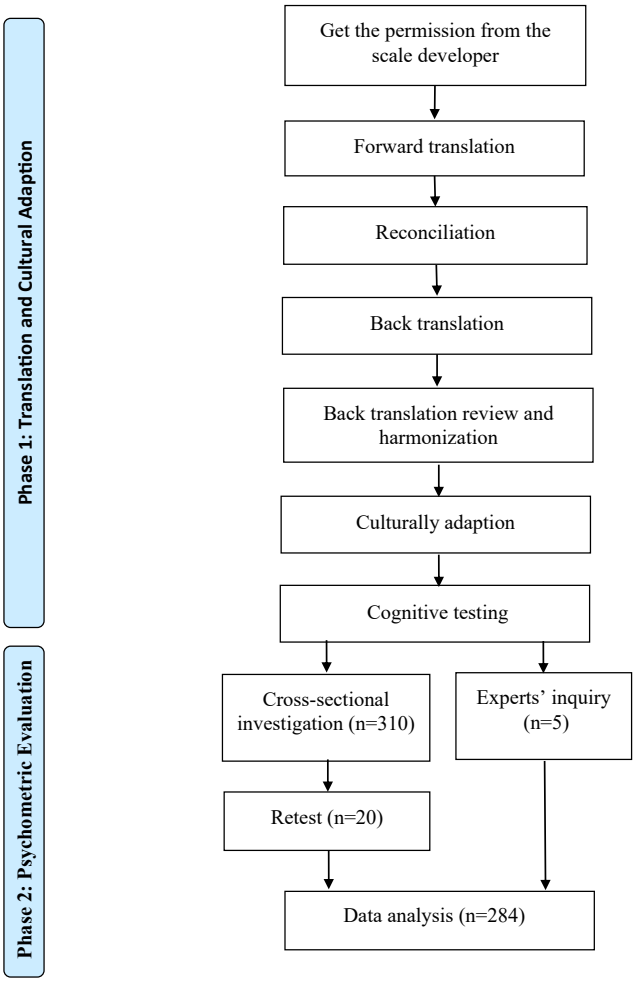

Fig. 1. Flow diagram

Phase 1: Translation and cultural adaption

After getting permission from the PCDS developer, we obtained both the English and Japanese versions of the PCDS (Appendices A and B). We translated and culturally adapted the English version of the PCDS into a Chinese version following the corresponding guidelines.[16,17] The Japanese version of the PCDS was used as a reference to ensure the accuracy of the translation and adaptation. The detailed steps were as follows.

Step 1: Forward translation

Two postgraduates in the nursing major who speak native Chinese and are fluent in English completed the forward translation independently, generating two versions of forward translations (FT1 and FT2).

Step 2: reconciliation

Reconciliation was carried out by discussions among the above two translators and another independent translator who had not been involved in the forward translation. After thorough discussions, a combined translation version was prepared (FT12).

Step 3: Back translation

Back translations were completed independently by two experts with doctoral degrees who had never seen the original version of the PCDS. The two translators had long-term study and work experiences in Hong Kong or overseas and could speak English as fluently as a native English speaker. After the completion of back translations, two English versions (BT1 and BT2) were formed.

Step 4: Back translation review and harmonization

A harmonization meeting, comprised of the project manager and the translators, was held to detect and deal with translation inconsistency among the different translation versions. If any discrepancies existed, clarification would be sought from the developer to ensure conceptual equivalence between all translation versions. After the harmonization process, a pre-final version A of the PCDS was formed.

Step 5: Cultural adaption

The cultural adaption was carried out by collecting opinions and evaluations on semantic equivalence and cultural applicability from different experts through emails. The inclusion criteria for experts were as follows: (1) having rich experience in the field of palliative care practice or methodology about cross-cultural translation; (2) having at least five-year work experience; (3) being willing to participate in this research. Finally, 7 eligible experts were invited to participate in this study. One of them is proficient in English, has long-term study experience in Japan, and is familiar with Japanese culture and language. All the 7 experts received the original English version of the PCDS, the pre-final version A, as well as all the other translated versions during this phase. Besides, we also sent the original Japanese version of the PCDS to the expert who is proficient in Japanese. All the 7 invited experts evaluated the semantic equivalence and cultural applicability based on a Likert four-point scale with responses ranging from 1 (not at all equivalent/applicable) to 4 (totally equivalent/applicable). In addition, they were required to propose detailed advice for any inappropriate translations.

These suggestions were collected to instruct the further improvement of the PCDS to form a pre-final version B. During this step, we continually kept in contact with the developer of the PCDS through emails.

Step 6: Cognitive testing

The final step is cognitive testing. We investigated 10 clinical physicians and nurses engaged in palliative care practice by convenience sampling. After completing the scale, the participants were interviewed about their understandings and suggestions on the pre-final version B. After this step, the Chinese version of the PCDS was formed (Appendix C).

Phase 2: Psychometric evaluation

Psychometric properties include validity (content and construct validity) and reliability (internal consistency reliability and test–retest reliability). After obtaining the ethical approval from the Institutional Review Board (No. IRB0001052-17027), the psychometric evaluation for the Chinese version of the PCDS was divided into two sections: expert consultations for content validity and a cross-sectional survey for the other psychometric properties.

Expert consultation

Expert consultations were conducted through emails to collect experts' opinions on content validity. The inclusion criteria for experts were as follows: (1) having rich experience in palliative care practice and research; (2) having been working at least for five years; (3) being willing to participate in this research. Finally, 5 eligible experts were invited to evaluate the correlation between each item and the measurement objectives based on a Likert four-point scale (1 = "Not at all related", 4 = "Very related").

Cross-sectional survey

Participants. According to the consensus-based standards for the selection of health measurement instruments (COSMIN) risk of bias checklist,[11] the sample size should reach seven times of the number of items for evaluation of the psychometric properties. Wu suggested that the sample size should reach 200 when performing confirmatory factor analysis (CFA) to ensure the statistical power for data analysis.[18] Estimating 20% of invalid responses, we planned to survey 250 participants by convenience sampling. The inclusion criteria were as follows: (1) nurses and physicians who had at least one-year experience in palliative care service; (2) those who gave consent to participate in this study.

Data collection. Affected by the COVID-19 pandemic, we adopted an online data collection method by sending the website link or QR code of the electronic questionnaire to the potentially eligible participants from November 2020 to December 2020. The electronic questionnaire includes three sections: (1) instructions and informed consent to explain the purpose of this study and the principle of anonymous, voluntary participation; (2) demographic characteristics including gender, age, educational level, and department belonging to; (3) the Chinese version of the PCDS. Finally, 310 completed questionnaires were received, with 284 valid responses, representing a response rate of 91.6%. To examine the test–retest reliability, we sent the Chinese version of the PCDS again to those who consented to participate in the second survey, and 20 valid questionnaires were received. The time interval for the test–retest reliability survey was around two weeks.[12]

Data analysis

Demographic characteristics were presented by frequencies and percentages. The scores of the PCDS were presented with means and standard deviations. All analyses were conducted using the SPSS 23.0 and Amos 24.0 software.

Floor and ceiling effects. The floor and ceiling effects were evaluated by the percentage of participants obtaining the lowest or highest possible scores on the PCDS. Floor or ceiling effects were considered absent if less than 15% of participants achieved the lowest or highest scores.[24]

Internal consistency reliability. Internal consistency reliability was evaluated by calculating Cronbach's α coefficients for each dimension and the total scale. It would be considered satisfactory if the Cronbach's α coefficients were higher than 0.70.[21] We also calculated the corrected item–total correlation coefficients to assess the internal consistency, which measured the correlation between the score of an individual item and the sum of the scores of the remaining items, among all the items. A value above 0.3 was considered acceptable.[22]

Test–retest reliability. The intra-class correlation coefficient (ICC) was calculated by applying the Spearman's Rho correlation analysis, with ICC $\geq$ 0.70 indicating good test–retest reliability.[21] ICC $>$ 0.60 was also considered acceptable.[23]

Content validity. The content validity index (CVI) was calculated at both the item level (I-CVI) and scale level (S-CVI) based on experts' scores. The I-CVI was calculated based on the proportion of experts who rated the item as 3 (related) or 4 (very related) on a Likert 4-point scale. The S-CVI was presented as the average value of I-CVIs. Content validity was considered satisfactory if I-CVI $\geq$ 0.78 and S-CVI $\geq$ 0.90.[19]

Construct validity. CFA was performed to test the five-factor structure of the original PCDS. Model fitness was assessed using a set of fit indices which included the chi-square/degrees of freedom ratio (χ^2/df), the root mean square error of approximation (RMSEA), the goodness of fit index (GFI), the Tucker–Lewis index (TLI), and the comparative fit index (CFI). A satisfactory model should meet the following criteria: χ^2/df $<$ 3.00, SRMR $<$ 0.05, RMSEA $<$ 0.08, GFI $>$ 0.90, TLI $>$ 0.90 and CFI $>$ 0.90.[18] In addition to model fit indices, item factor loadings were also examined to identify poorly fitted items. A cutoff of 0.40 was used for item inclusion.[20]

Results

Translation and cultural adaption

Discrepancies mainly existed in step 4 (back translation review and harmonization) and step 5 (cultural adaption). The first issue was about the target patients receiving palliative care in the scale. The original scale targeted at cancer patients in the dying phase. After discussion in the harmonization meeting and communication with the developer, we translated "cancer patients in the dying phase" into "patients at the end of life". In addition, one of the experts identified that there was overlap between item 7 "It is difficult to get support from experts about alleviating symptoms" and item 8 "There is no expert whom I can consult with about alleviating symptoms," By checking with the developer, we learned that item 7 emphasized that there was a palliative care team but medical staff could not consult the palliative care team because "Physician are reluctant to ask nurses" or "They are too busy"; while Item 8 meant that there were no palliative care experts. Therefore, we further illustrated the difference between these two items by introducing an example "such as experts are busy" in item 7. No other discrepancies were identified about the Chinese version of the PCDS. During the cognitive testing, all the 10 participants thought all the items were well-articulated and the meaning was easy to be understood. No changes were

Table 1
The items of the PCDS in both English version and Chinese version.

Items	English version	Chinese version
1	The method of evaluating symptoms is not consistent in multi-professional teams.	医护等不同专业人员评估症状的方法不一致
2	It is difficult to have a common goal toward alleviating symptoms in multi-professional teams.	医护等不同专业人员难以设定缓解症状的共同目标
3	It is difficult to communicate about alleviating symptoms in multi-professional teams.	医护等不同专业人员关于症状缓解的沟通有困难
4	When a patient expresses anxiety, it is difficult to respond.	当患者表露出焦虑时，应对有困难
5	When a family expresses anxiety, it is difficult to respond.	当患者家属表露出焦虑时，应对有困难
6	After a patient is informed of bad news, it is difficult to talk.	在患者被告知不好的消息后，与患者的沟通有困难
7	It is difficult to get support from experts about alleviating symptoms.	在症状缓解方面，获取专家的支持有困难（如专家太忙）
8	There is no expert whom I can consult with about alleviating symptoms.	在症状缓解方面，没有可以咨询的专家
9	There are no facilities that can be consulted for alleviating the symptoms of home-care patients.	在居家患者的症状缓解方面, 没有可以咨询的机构.
10	There is a lack of knowledge about alleviating cancer pain.	缺乏缓解临终患者疼痛的知识
11	There is a lack of knowledge about alleviating dyspnea and digestive symptoms.	缺乏缓解呼吸困难和消化系统症状的知识
12	Necessary training is not received about palliative care.	没有接受过必要的安宁疗护培训
13	There is no meeting between facilities when the cancer patient moves from hospital to home care.	当临终患者从医院转移到居家护理时，医疗机构之间没有相应的会议沟通。
14	It is difficult to get information about home care for cancer patients.	获取临终患者居家护理的信息有困难
15	It is difficult to share information between hospital and facilities that provide home care.	医院和居家护理机构之间信息共享有困难

PCDS: palliative care difficulties scale

made according to the cognitive testing results. All the PCDS items of both the English version and the final Chinese version are listed in Table 1.

Psychometric evaluation

Demographic characteristics

In total, 284 valid questionnaires were included in our analyses. No missing data existed because each item in our electronic questionnaire was required to be completed. The collected data were from 281 nurses and 3 physicians, 20 of whom completed the retest. Detailed demographic characteristics of the participants are listed in Table 2.

Floor and ceiling effects

The scores for each item of the PCDS are listed in Table 3, and the dimension scores are summarized in Table 4. The lowest and highest total scores for the PCDS were 15 and 90, respectively. Only 1.1% and 1.8% of the participants achieved the lowest and highest scores, respectively. Thus, neither floor nor ceiling effects existed according to the definition of floor and ceiling effects.

Internal consistency reliability

Internal consistency reliability for the whole scale was 0.94. Cronbach's α coefficients for each dimension of the PCDS ranged from 0.84 for expert support to 0.92 for community coordination (Table 4). All the corrected item–total correlation coefficients ranged from 0.54 to 0.75 (Table 3).

Table 2
Demographic characteristics ($n = 284$)

Demographic characteristics	*n*	%
Gender		
Male	14	4.9
Female	270	95.1
Age (years)		
< 30	111	39.1
30–39	134	47.2
≥ 40	39	13.7
Educational level		
College degree and below	74	26.1
Bachelor degree and above	210	73.9
Profession		
Physicians	3	1.1
Nurses	281	98.9
Departments/units		
Palliative care unit	17	6.0
Department of geriatrics	18	6.3
Intensive care unit	33	11.6
Department of oncology	80	28.2
Others	136	47.9
Work experience (in years)		
< 5	85	29.9
5–9	94	33.1
≥ 10	105	37.0

Table 3
The item scores and corrected item–total correlation coefficients ($n = 284$).

Items	The shortened names of each item	Mean	SD	Corrected item–total correlation coefficients
1	Inconsistent methods of evaluating symptoms.	3.35	1.23	0.62[a]
2	Difficulties to have a common goal toward alleviating symptoms.	3.17	1.31	0.66[a]
3	Difficulties to communicate about alleviating symptoms.	2.91	1.21	0.72[a]
4	Difficulties to respond to patients' anxiety.	3.05	1.20	0.70[a]
5	Difficulties to respond to families' anxiety.	3.07	1.14	0.73[a]
6	Difficulties to talk after a patient gets bad news.	3.07	1.13	0.72[a]
7	Difficulties to get support from experts.	2.98	1.30	0.73[a]
8	No expert for consultation about alleviating symptoms.	2.83	1.34	0.73[a]
9	No facilities for consultation for home-care patients.	3.22	1.45	0.74[a]
10	Lack knowledge about alleviating cancer pain.	2.79	1.23	0.74[a]
11	Lack knowledge about alleviating dyspnea and digestive symptoms.	2.84	1.21	0.75[a]
12	Necessary training is not received.	2.89	1.50	0.54[a]
13	No meeting between facilities for patient referral.	3.29	1.49	0.66[a]
14	Difficulties to get information about home-care patients.	3.35	1.42	0.70[a]
15	Difficulties to share information between facilities.	3.47	1.41	0.74[a]

SD, standard deviation.
[a] $P < 0.01$.

Test–retest reliability

The ICC for the scale was 0.66, and the ICCs for each dimension ranged from 0.41 (alleviation of symptoms) to 0.65 (expert support). Detailed results are listed in Table 4.

Table 4
The scores and reliability ($n = 284$).

The PCDS	Mean	SD	Cronbach's α	ICC
Different dimensions of the PCDS				
Communication in multidisciplinary teams	9.44	3.35	0.87	0.58[a]
Communication with the patient and family	9.18	3.20	0.91	0.62[a]
Expert support	9.02	3.56	0.84	0.65[a]
Alleviation of symptoms	8.52	3.46	0.84	0.41
Community coordination	10.11	4.02	0.92	0.57[a]
The PCDS	46.27	14.49	0.94	0.66[a]

PCDS, palliative care difficulties scale; SD, standard deviation; ICC, intra-class correlation coefficient
[a] $P < 0.01$.

Content validity

For content validity, all the experts considered that all the items were related or very related to the measurement purpose of the PCDS. The values of I-CVI and S-CVI were equal to 1.

Construct validity

CFA verified that the five-factor model had a satisfactory model fit with $\chi^2/df = 2.683$, SRMR = 0.047, RMSEA = 0.077, GFI = 0.912, CFI = 0.964 and TLI = 0.950. The standardized factor loadings for each item were significant and ranged from 0.62 to 0.96. No items would be removed according to the results. Detailed results are shown in Fig. 2.

Discussion

Palliative care services in China have been developing rapidly in recent years, albeit with difficulties and challenges.[8,25] In response to the need for palliative care development, we translated and culturally adapted the PCDS into a Chinese version and comprehensively evaluated the psychometric properties of the Chinese version of the PCDS. The results showed that the Chinese version of the PCDS was a valid and reliable tool for the assessment of difficulties perceived by clinical nurses and physicians, and had the great potential for further use in Chinese palliative care practice. This study also provided an example that the PCDS could be applied in other developing countries by appropriate cultural adaptions.

Throughout the process of cultural adaption, we followed the recognized guidelines and kept communications with the original scale developer whenever we encountered disagreement and uncertainty. In view of semantic equivalence and cultural applicability, we invited an expert familiar with Japanese culture for the cultural adaption. It is great helpful for us to accurately understand the meaning of each item under the source cultural background. With the help of the experts and original developer, we made some modifications to the original version of the PCDS to make it more suitable for Chinese culture. We widened the target population receiving palliative care from cancer patients to patients with all kinds of advanced disease who are at the end of life, which complied with the growing demands for palliative care. With the development of palliative care, palliative care services are not only for cancer patients but also for all patients living with advanced illnesses.[26] As a summary,

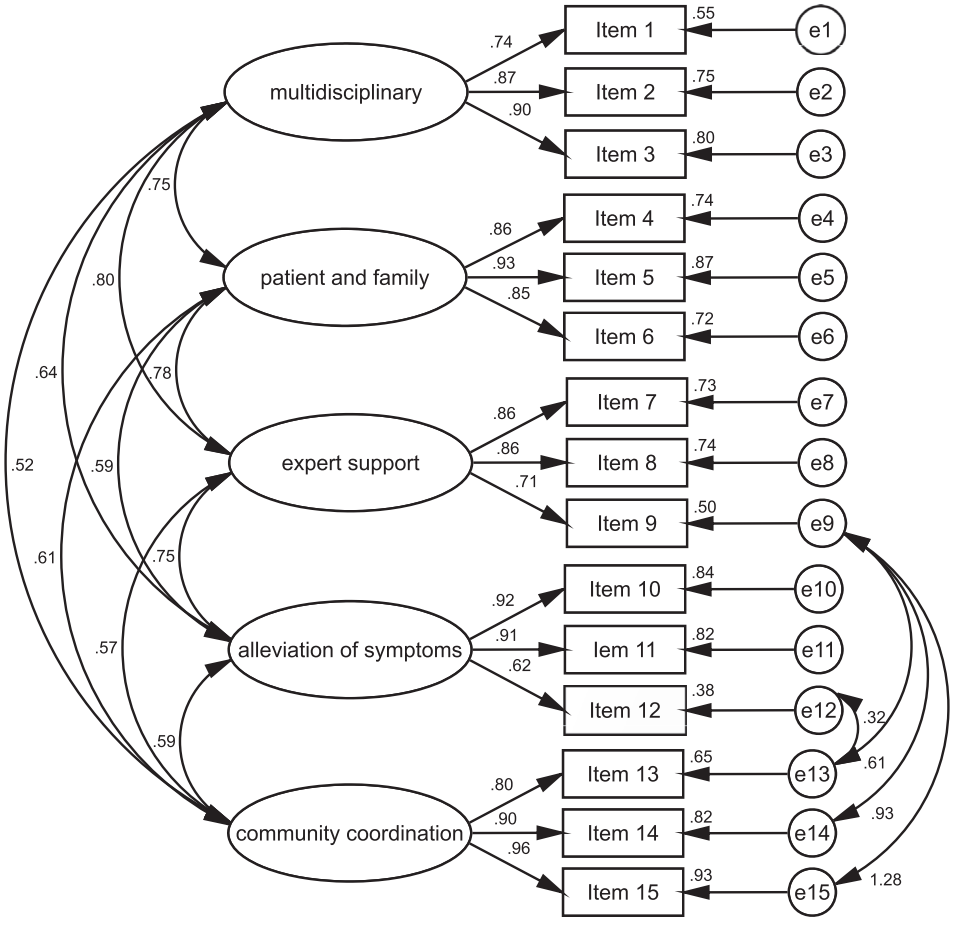

Fig. 2. Confirmatory factor analysis

considering both Chinese traditional culture about palliative care and the current status of clinical palliative care practice, we translated cancer patients into patients at the end of life. In addition, to further clarify the differences between item 7 and item 8, we introduced an example in item 7. All these changes were made after communication with the developer of the PCDS and experts in the palliative care field.

For the psychometric properties, the analysis revealed that the Chinese version of the PCDS had a satisfactory internal consistency, which was consistent with the original version and the Spanish version.[12,15] Cronbach's α coefficients of both the whole scale and each dimension were higher than 0.7, and all the item–total correlation coefficients were above 0.3. However, compared with the internal consistency reliability, the test–retest reliability was only barely satisfactory. The ICC for the total score of the Chinese version of the PCDS (0.66) did not reach a satisfactory level but was acceptable, which was similar to the original version showing ICCs ranging from 0.61 to 0.69 for each dimension.[12] The dimension of alleviating symptoms had the lowest and insignificant ICC. On the one hand, it might be owing to the small sample size for retest. Further examination for test–retest reliability should be conducted in studies with larger sample sizes from different disciplinary fields in the future. On the other hand, given that this dimension mainly measured the extent of knowledge deficiency for alleviating symptoms, participants might obtain some new knowledge from clinical practice, training and other channels during the two-week interval, which might affect the test–retest reliability. From another point of view, the result also implied that the difficulties about knowledge insufficiency might be relatively easier to be overcome in a short period of time compared with the other difficulties. Besides, another possible explanation for the unsatisfactory test–retest reliability was that the PCDS score mainly reflected the subjective perceptions of participants, which was easy to be influenced by their emotional state at the moment of evaluation.

As for content validity, all the experts unanimously thought that each item in the PCDS could adequately reflect the purpose of the measurement. The CVI values (equal to 1) from experts' judgment revealed that the Chinese version of the PCDS had excellent content validity. Meanwhile, CFA verified that the five-factor structure of the original PCDS had a satisfactory model fit.[12] All the factor loadings in each dimension were above 0.6, which further confirmed the stability of the five-factor structure.[20] Our results were consistent with that of the original PCDS, showing fairly good validity when compared with similar tools.[12,27]

Strengths and limitations

The main strength of this study is that we adopted a rigorous methodology in the translation and cross-cultural adaptation process based on guidelines, which ensured the scientificity and preciseness of the research. Moreover, we invited an expert familiar with three languages (Chinese, English, and Japanese) for the cultural adaption, which further ensured the quality of the phase 1 procedures. However, limitations also existed in this study. Firstly, the participants who were investigated in phase 2 were mostly nurses, with only 3 physicians included. All the 20 participants who completed the retest were nurses. Therefore, the results should be further verified in different medical staff. Additionally, we did not evaluate the criterion validity of the Chinese version of the PCDS due to a lack of relevant criterion tools.

Conclusions

We translated and culturally adapted the PCDS into a Chinese version. The results of psychometric evaluation showed that the Chinese version of the PCDS was a reliable and valid tool for potential use in Chinese palliative care practice. Considering the limited sample size of this study, we suggest future studies should focus on performing psychometric testing of the Chinese version of the PCDS in more diversified medical staff cohorts with larger sample sizes. Overall, this study provided a new and validated tool for Chinese medical staff and managers to assess the difficulties and barriers in clinical palliative care practice. It might be beneficial for the future improvement of palliative care services. Meanwhile, the scores of the Chinese version of the PCDS can also be used to evaluate the efficacy of the training programs or policies implementation of palliative care.

Authors' contributions

Conceived and designed the analysis: Qiaoqin Wan, Xiuxiu Huang, Xiaoyan Zhao, Xiaohong Ou, Yuan Qin. Collected the data: Xiuxiu Huang, Xiaoyan Zhao, Xiaohong Ou, Yuan Qin. Contributed data or analysis tools: Xiuxiu Huang, Xiaoyan Zhao. Performed the analysis: Xiuxiu Huang, Xiaoyan Zhao. Wrote the paper: Xiuxiu Huang, Qiaoqin Wan

Funding

Nil.

Declaration of competing interest

None declared.

Ethics statement

This study was obtained the ethical approval from the Institutional Review Board of Peking University (Approval No. IRB0001052-17027).

Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.apjon.2022.03.003.

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