Article:

Zheng, X., Zhao, J., Mayland, C.R. orcid.org/0000-0002-1440-9953 et al. (6 more authors) (2025) Translation and cultural adaptation of the Chinese version of the International ‘Care Of the Dying Evaluation’ (CODE™) tool for assessing the quality of care for dying patients from the perspective of bereaved family members. BMC Palliative Care, 24 (1). 128. ISSN 1472-684X

https://doi.org/10.1186/s12904-025-01772-9

Zheng *et al. BMC Palliative Care (2025) 24:128*
https://doi.org/10.1186/s12904-025-01772-9

BMC Palliative Care

RESEARCH **Open Access**

Translation and cultural adaptation of the Chinese version of the International 'Care Of the Dying Evaluation' (CODE™) tool for assessing the quality of care for dying patients from the perspective of bereaved family members

Xuejiao Zheng[1,2*], Juanjuan Zhao[3], Catriona R. Mayland[4,5], Lei Dong[1], Feixue Cong[2], Xijia Zhang[2], Ya Wen[2], Dong Xie[6] and Mitsunori Miyashita[1]

Abstract

Background Culturally appropriate assessments are needed to improve care during the last days of life. One way of assessment is to use a tool with bereaved family members after death. The aim of this study was to translate and cross-culturally adapt the International 'Care Of the Dying Evaluation' questionnaire (i-CODE) into Mandarin Chinese.

Methods Translation and cultural adaptation process was performed according to the Brislin Classical Backtranslation Model and the principles of the European Organization for Research and Treatment of Cancer (EORTC) quality-of-life group translation procedure. Fifteen bereaved family members, 5 palliative care experts and 4 translators were involved in the process, which followed 10 steps: a) Preparation; b) Forward translation; c) Reconciliation; d) Backward translation; e) Reconciliation; f) Backward translation review; g) Expert consultation; h) Cognitive interview; i) Cognitive interview review; h) Final proofreading.

Results The translation and cultural adaptation followed established guidelines. items 1 ("washing"), 2 ("giving medicines"), 14 ("noisy rattle"), 18 ("giving fluids through a 'drip'") emerged divergence and reached a consensus among the research team, translators, and original author. In the cultural adaptation, demographic items were restructured to align with Chinese context. Gender-neutral terminology was employed by using "they/them". Inconsistent subject, terminology "healthcare team" and Items 4 ("had adequate privacy"), 14 ("noisy rattle"), 27 ("in the right place"), and 28 ("at the actual time of his/her death") was modified based on experts' assessments and bereaved families' comments. Linguistic, cultural, and conceptual equivalence was achieved in the process of translation and cultural adaptation.

---

*Correspondence:
Xuejiao Zheng
zheng.xuejiao.r8@dc.tohoku.ac.jp
Full list of author information is available at the end of the article

Conclusion A questionnaire allowing for international comparisons related to quality of care for dying individuals has been developed in Mandarin Chinese. Key cultural adaptations were required to ensure that the Chinese version of the i-CODE was suitable for use. It has proved content and face validity. Future work will focus on psychometric testing assessing the validity and reliability of questionnaire and its use in assessing and improving care.

Keywords Palliative care, Bereaved family members, Cultural adaptation, Equivalent translation, Quality of care for the dying

Background

With the acceleration of population aging, as well as the increase in chronic diseases and cancer [1–4], the demand for palliative care will continue to increase worldwide. China's population accounts for approximately one-fifth of the world's total population, although the quality of care for dying patients has improved gradually in China [5], there is still a significant gap between China and some European countries [6]. As reported in 2021 Global Quality of Death, United Kingdom ranked 1 st, and China ranked 53rd in the evaluation of death quality in 2021 [7]. Less than 1% of Chinese people can access palliative care [8], indicating an enormous potential demand for palliative care in China. To improve the quality of care for dying patients, accurately assessing the current quality of care is fundamentally important. As family carers play an important role in supporting dying individuals [9, 10], one method for assessing the quality of care for dying patients is to use the views of bereaved family members [11–13].

International 'Care Of the Dying Evaluation' (i-CODE) questionnaire is a self-completion questionnaire used with bereaved family members, focused on both quality of care and level of family support on last days of life. I-CODE questionnaire was internationally validated in a study involving 7 European and South American countries and has demonstrated robust reliability and validity in evaluating the quality of care given in the last days of life for dying patients [14, 15], and has been adapted in 11 languages [16], such as German, Norwegian, Polish, Swedish and so on.

We aimed to translate and cross-culturally adapt i-CODE to obtain a version with content and face validity in Chinese. Although assessment tools have been developed to measure the progress made of palliative care in China [17–19], it is crucial to have a validated international tool for evaluating the quality of care for dying patients for the good development of palliative care research in the Chinese context. The objectives of our study were to outline the process involved in cross-cultural adaptation, to emphasize the primary challenges faced during this process, and to review various strategies that could help overcome or address these issues.

Methods

I-CODE questionnaire

The i-CODE consists of 32 main questions and 10 additional questions (demographic details) [20]. The 32 main questions for evaluating nursing and medical care, symptom control, communication with the healthcare team, emotional and spiritual support, death circumstances, and overall impressions are scored with both nominal and ordinal response options (5-point (0–4), 4-point (0–3) or 3-point (0–2) Likert scale).

Process of translation and cross-cultural adaptation

The process integrated principles from Brislin's Classical Back-Translation Model [21] for initial linguistic validation and the EORTC translation guidelines [22] for clinical relevance assurance. This approach ensured both conceptual equivalence via dual forward/backward translations and cross-cultural adaptation through expert consultation and cognitive interviews. The process was carried out in 10 steps, as summarized in Fig. 1.

Step 1: Preparation

In the initial preparatory stage of translation and cross-cultural adaptation, we contacted the author of the original i-CODE questionnaire by e-mail, explaining the purpose of the study, the translation plan, and obtained the written permission. This process was in accordance with the EORTC translation guidelines on "obtaining permission from the authors of the original scale". Subsequently, a multidisciplinary research team was assembled, including palliative care experts, linguistic experts, clinical experts, and methodological experts, to ensure a professional and multidimensional translation and adaptation process. During the translation process, Mandarin (Putonghua), as the official language, was confirmed as the language of the questionnaire to ensure its generalizability and operability across the country.

Step 2: Forward translation

According to the first step of Brislin's Classical Back-Translation Model, we invited two bilingual translators (T1 and T2) to independently translate the English version of i-CODE into Chinese. T1 is a PhD student with palliative care-related knowledge and proficiency in

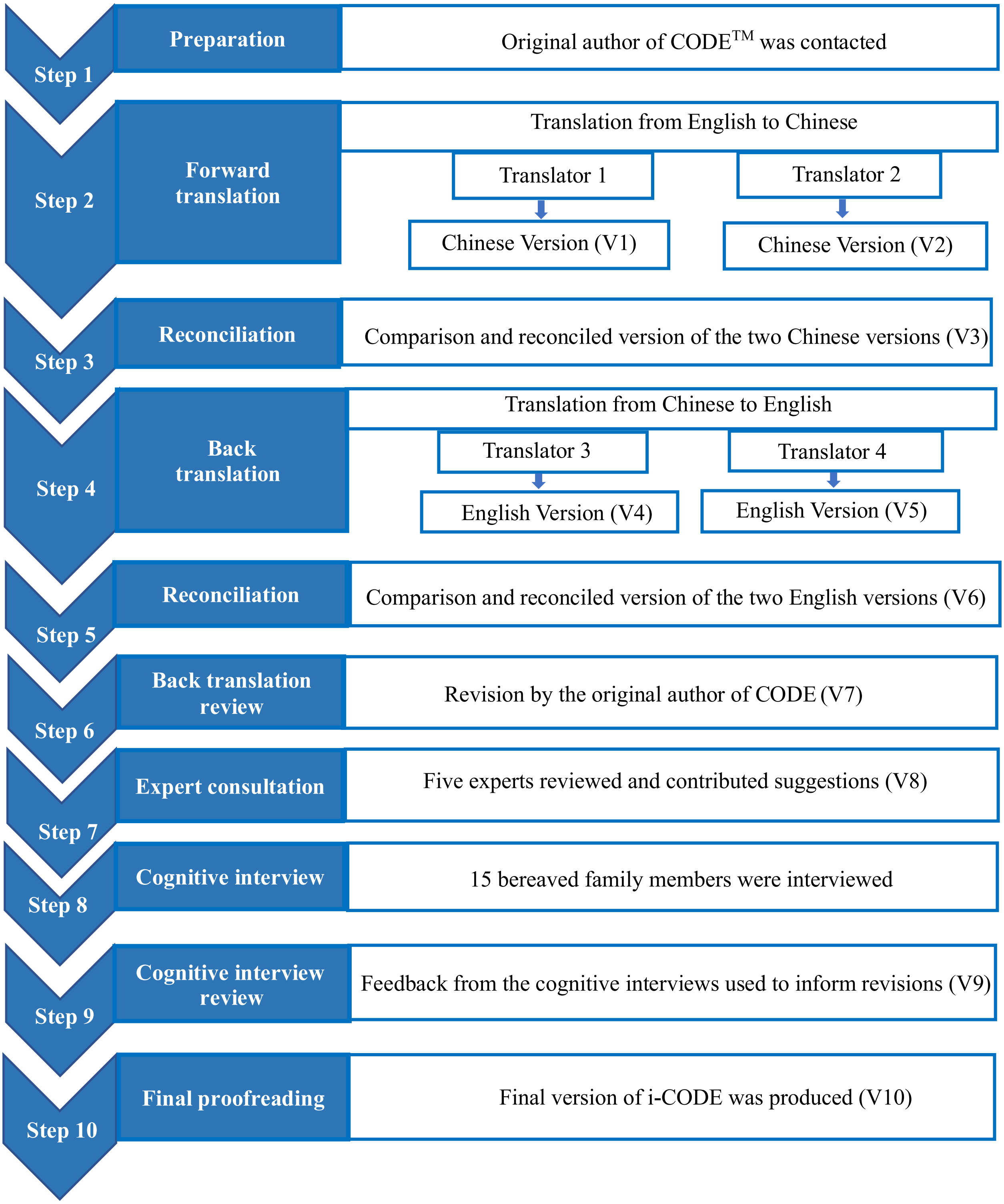

Fig. 1 The flowchart of the translation and cross-cultural adaptation of i-CODE from English into Chinese

English, and T2 is an English teacher at a university with a master's degree in English Language and Literature and is proficient in both English and Chinese language expressions. Each of the two translators completed the translations unknowingly, generating two Chinese versions (V1 and V2). This process aimed to minimize the influence of subjective bias in the translation process and to ensure the independence and diversity of the translation results.

Step 3: Reconciliation

After completing the initial translation, the research team held a discussion meeting with T1 and T2 to compare V1 and V2 item by item in accordance with the requirements of "translation consistency" in the EORTC guidelines. The focus was on semantic, contextual, and cultural differences to ensure the accuracy of the translation results in terms of linguistic expression and conceptual transfer. At the same time, the cultural appropriateness of key specialized terms and phrases in the questionnaire was reviewed to ensure their applicability in the Chinese cultural context. Through discussions, the research team reached a consensus and integrated to generate a single Chinese translation version (V3).

Step 4: Backward translation

The purpose of this step is to perform a validity check of the version obtained through forward translation. According to the second step of Brislin's model, two translators (T3 and T4) with overseas study background were invited to independently back-translate V3 into English, generating two back-translated versions (V4 and V5). T3 has a background in nursing knowledge, while T4 was unfamiliar with this domain, neither T3 nor T4 had been exposed to the original questionnaire to minimize the subjective bias that might occur in the back-translation process. Back-translation was used to verify the accuracy of the forward translated version and the extent to which the meaning of the original questionnaire was retained, ensuring that the translated version was accurate compared to the original instrument in the source language. In addition, it helps to identify and resolve any inconsistencies and conceptual errors.

Step 5: Reconciliation

After completing the backward translation, the research team held discussions with T3 and T4 to jointly review the differences between V4 and V5. The item-by-item comparison and discussion resulted in the generation of a consistent back-translated version (V6). This version was then sent to the author of the original questionnaire for review to ensure that the back-translated results were accurate and that the meaning of the original questionnaire had not been misinterpreted.

Step 6: Backward translation review

The author of the original questionnaire reviewed V6 in detail and suggested changes. Based on the original author's feedback, the research team revisited the Chinese translated version (V3) and adjusted some of the translations as needed. Subsequently, the research team repeated the process of forward and backward translation until agreement was reached with the author of the original questionnaire, generating the final revised back-translated version (V7). This process strictly followed the requirements of the Brislin's model of "original author validation" to ensure the accuracy and cross-cultural adaptability of the translation results.

Step 7: Expert consultation

In accordance with the EORTC Translation Guidelines for Expert Review, we invited five experts with more than 10 years of either clinical or research expertise in the field of healthcare treatment to review V7. The expert panel included a physician, two nurses, an Nursing English educator, and a palliative care expert. The review included content validity, language clarity, and cultural appropriateness of the questionnaire items. Through independent review and group discussion, the experts suggested some changes to the questionnaire items. Based on the experts' comments, the research team further revised the questionnaire and generated a Chinese version (V8) that is more suitable for the Chinese cultural context.

Step 8: Cognitive interviews

We performed cognitive interview to further validate the cultural appropriateness and linguistic comprehensibility of the questionnaire. Cognitive 'think aloud' interviewing, which involved training respondents to articulate their thoughts as they read a question; recall from their memories the information required; and turn the information they have into an answer [23], was conducted in the study. "Snowballing sampling" was used to recruit participants, who were aged ≥ 18 years old, were the main caregivers of bereaved patient (died in the hospital, age of deceased patient ≥ 18 years, inpatient treatment ≥ 72 h, time of death ≥ 3 months; the patient not died in the intensive care unit or treatment-related death (e.g. surgical complications, severe drug allergy), had basic Chinese reading and writing abilities, and could complete questionnaire surveys. A mutually suitable time and place was arranged for the one-to-one interview to occur. Following oral informed consent, a structured cognitive 'think aloud' interview [24] was conducted by research team. The important viewpoints and information were noted down during the interview. If the respondents' expressions were unclear or further in-depth understanding was needed, the researcher promptly asked follow-up questions to ensure that comprehensive and accurate information was obtained. All cognitive interviews were conducted online through Zoom or Tencent Meeting.

Step 9: Cognitive interview review

After the interview, the researcher rechecked the content recorded and marked in the interview to ensure that no important information was missed. If any unclear suggestions or views requiring supplementation were found, the researchers promptly contacted the respondents for confirmation. Based on the feedback from the cognitive interviews, the research team carefully revised the content of the questionnaire in five aspects: comprehensibility, cultural relevance, emotional acceptability, terminological consistency, and response burden, resulting in the Chinese version of the i-CODE (V9).

Step 10: Formation of the Chinese version of the i-CODE

After completing all the above steps, the research team generated the final Chinese version of the i-CODE questionnaire (V10) based on V9. The research team thoroughly checked the grammar of V9, corrected all linguistic errors, and adjusted the layout of the questionnaire according to Chinese expression habits to improve the readability and aesthetics of the questionnaire. The V10 met the requirements of the EORTC Translation Guidelines and the Brislin's Backward-Translation Model in terms of linguistic expression, cultural adaptation, and content validity, and provides a reliable basis for subsequent research.

Results

Challenges highlighted in step 1 (preparation)

Through obtaining written permission from the original author, the legality and standardization of the translation were ensured, while duplicate translations were avoided, mitigating potential legal issues. The establishment of a multidisciplinary team ensured the professionalism of language translation, cultural adaptability, and clinical applicability. During the translation process, Mandarin (Putonghua), as the official language, was confirmed as the language of the questionnaire to ensure its generalizability and operability across the country. The original i-CODE consisted of 32 core items and 10 demographic information items. We removed item 35 and 40, which involve "ethnic group" in the original questionnaire. Therefore, 32 core items and 8 demographic information in the Chinese version of i-CODE.

Challenges highlighted in step 2 and 3 (forward translation and reconciliation)

V1 and V2 were mostly consistent. However, aside from minor differences in grammar and syntax, dissimilar translations were identified in item 1 "washing", item 14 "noisy rattle", item 27 "in the right place", item 28 "the actual time of his/her death", item 29 "sensitive manner", and the terminology "healthcare team". The differences were not only semantically modified but also adjusted according to the cultural background. Through joint discussion among T1, T2, and a member of the research team, consensuses were reached for all the above items except an item ("noisy rattle"). During the forward translation process, two translators both noticed the issue of inconsistent subjects in the questionnaire. The overall design of the questionnaire used the second person "you" for asking the respondents, for example, "Were you told…". However, it was found that items 22 and 28 were stated as first person "my …. were met" and "I was". We had unified the subject and used the second person "you" throughout the questionnaire.

Challenges highlighted in step 4 and 5 (backward translation and reconciliation)

Two independent translations, V4 and V5, agreed most of the time in terms of semantics, sentence structure and expression, except for four items. Although the two translations of Item 27 were the same, they do not conform to the original item. In the three items (item 2 "giving medicines", item 28 "at the actual time of his/her death", and item 29 "sensitive manner"), none of the backward translations matched the original i-CODE. Two of these ("noisy rattle" and "at the actual time of his/her death") were already highlighted from the forward translation as potentially problematic. T3, T4 and a member of the research team discussed these dissimilarities in order to find the best alternative.

Challenges highlighted in step 6 (backward translation review)

V6 was sent to the original author for review. One of the adjustments at this step was the adoption of gender-neutral language. Gender-neutral language (they/them) was proposed to refer to the deceased patients, according to the revised original questionnaire. Another issue that was brought up and resolved during the original author review was the translation of the term "healthcare team". Initially, we translated "healthcare team" as 医疗团队(medical team). However, upon further consideration and in consultation with original author, we decided to adopt the translation "健康照护团队", which not only places emphasis on the medical and clinical aspects, but also the includes the non-medical but still crucial members of the care team, such as social workers and psychological counsellor.

In addition, the original author questioned the backward translations of three items, which were highlighted in previous steps. The original author indicated that item 27 "in the right place" and item 28 "the actual time of his/her death" in the back translation, not accurately convey the original meaning. The item 14 "noisy rattle" needs to be rigorously discussed to ensure accurate localization in Chinese. The original author review enhanced the semantic precision and cultural appropriateness.

Challenges highlighted in step 7 (expert consultation)

The expert consultation made the contributions to address unresolved translation challenges and to identify potential methodological issues or cultural biases in the translated questionnaire. The review of five experts with extensive clinical or research experience led to precise revisions, ensuring the cultural relevance, linguistic clarity, and content validity of the questionnaire.

Item 4 – "had adequate privacy"

Some expert consultation members pointed out that item 4 ("The bed area and surrounding environment had adequate privacy for him/her.") was ambiguous, which we didn't noticed in the previous steps. Item 4 described whether the bed area and its surrounding environment have sufficient privacy conditions for patient. In other word, patient's private space was well protected in this bed area and its surroundings, not easily disturbed by others, and can have a relatively private space to rest, relax or engage in some private activities. The bed area and surrounding environment enabled patient to enjoy sufficient privacy in this space. In accordance with the experts' suggestions, we decided to modify item 4 into the content recommended by the experts.

Item 14 – "noisy rattle"

The translation of item 14 ("In your opinion, during the last two days, did he/she appear to have a 'noisy. rattle' to his/her breathing?") remained a contentious issue after the backward translation and reconciliation process. The item was initially translated during step 2 by呼吸困难and嘈杂的呼吸音. After the discussion of forward translation reconciliation, we selected the term 明显的咕噜咕噜声that the sound that comes out of a patient's throat when they breathe, similar to the sound of gas passing through a liquid. During the Step 3, the item was translated respectively "noticeable purring" and "noticeable snorting", both did not match the original formulation. We discussed with the T3 and T4, they opted for明显的咕噜咕噜声. "Noisy rattle" here can be understood as a "noisy, rattling (or snoring-like) sound" during breathing. Expert consultation did not reach a consensus for "noisy rattle", they suggested alternatives (明显的喘息声, 呼吸痰鸣音, 喉咙呼噜声).

Item 27 – "in the right place"

The term "in the right place" was another item that faced challenges during the backward translation review process. T3 and T4 both translated the item as "in the best place", which original author noted that it did not fully capture the original meaning in the source questionnaire. Item 27 was whether the place of death conforms to patient's or the family's wishes. The item "in the right place" emphasized the appropriateness from the perspective of the patient's psychological expectations. For example, if a patient hopes to pass away peacefully at home and eventually does die at home, this expression can be used to ask others for their opinions. We accepted the original author's suggestion and, following expert review, ultimately translated it as "在合适的地点".

Item 28 – "the actual time of his/her death"

During the expert consultation step, the experts also raised concerns regarding the translation of the term "at the actual time of his/her death" as "in his/her terminal moment". The experts pointed out that while "terminal moment" may seem to convey a similar meaning, it failed to accurately convey the specific time point that was originally intended. The term "terminal" was more frequently associated with describing the dying process or the final stage of life rather than being directly used to describe the exact moment of death. To address this issue, "at the actual time of his/her death" based on the experts' feedback, was carefully revised as "在他/她去世的时候". This adjustment improved the naturalness and semantic accuracy of the translation.

Challenges highlighted in step 8 and 9 (cognitive interview and review)

The cognitive interview step aimed to further validate the cultural appropriateness and linguistic comprehensibility of the questionnaire. The following were the key challenges and findings identified during these two steps.

Item 14—"noisy Rattle"

During the cognitive interviews, it was revealed that the translation of the term "noisy rattle" presented certain challenges in terms of comprehension among family members, which could potentially impact subsequent psychometric tests. Specifically, while some experts had suggested translating "noisy rattle" as "明显的喘息声", it did not seem to be clearly understood by family members. One family member asked it ("what's the meaning of '明显的喘息声', does it mean, was there phlegm in patient's throat?"), another family member associated it to having short of breath. In expert consultation, other experts proposed alternative translations, such as "呼吸痰鸣音" or "喉咙呼噜声". The use of these more specific and detailed terms was found to assist family members in better understanding the nature of the term being described. We discussed with family members and reached a consensus on using "呼吸时有明显的痰鸣音(喘息声)" in the questionnaire.

Item 19 -in a way you found easy or difficult to understand

Another adaptation which is noteworthy relate to on the phrasing "in a way you found easy or difficult to understand?". Some family members noted that it seemed somewhat overly verbose. The complete sentence was "Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?". To maximize the conceptual equivalence, we did not alter the sentence structure during the Chinese translation process. Our translation of this sentence was "……. 您认为容易理解还是难以理解?. Although this sentence was generally well understood by family members, over half of them indicated that the expression was somewhat verbose and could be streamlined for better comprehension. After discussion among the research team members, we revised the sentence to "……是否让您觉得容易理解" or "……是否清晰易懂". Family members found such translations to be acceptable and understandable. This new sentence aligned more closely with the Chinese formulation, simplifies the question, and facilitates more accurate responses from family members.

Likert response options– "not sure" & "don't know"

Another issue that was brought up during the cognitive interview was the two response options, "not sure" and "don't know". For Item 27 ("In your opinion, did he/she die in the right place?"), the Likert response options were "yes……", "no……", "not sure" and "don't know". Among the family members, only two were able to distinguish the difference between "not sure" and "don't know", while the remaining 13 family members stated that these two options meant the similar meanings and it didn't matter which one they chose. Nevertheless, after discussion within the research team, we decided to keep these two response options unchanged to maintain consistency with the original questionnaire in this study, while keeping track of this potential bias during the psychometric validation.

Overall impression of participants

Family members hold positive attitudes towards the questionnaire and were willing to participate. They believed the content was relevant to the research topic and crucial to the quality of palliative care. No significant negative emotions were reported, indicating a high level of emotional acceptability. The questionnaire was understandable, two family members of whom pointed out terminology and complex sentence structures used in the questionnaire might be a bit confused and took more time to think before answering. This suggested the necessity for further clarification or simplification to ensure that family members could easily understand.

Challenges highlighted in step 10 (final proofreading)

To ensure the quality and validity of the questionnaire, the research team not only conducted repeated proofreading for the issues involved in the above steps but also took the following measures:

Standardization of terminology

The terms in the questionnaire were unified to maintain overall consistency and facilitate comprehension by respondents. For instance, although "died/dying/death" have multiple translations in Chinese, we consistently used the term "离世" to express this concept throughout the questionnaire.

Expression optimization

For overly professional, abstruse vocabulary and complex sentence structures, we used simple and straightforward language to clarify the meaning, making the questionnaire accessible to the average educational and linguistic level of the public. For example, in Item 1, "washing" was translated as "洗澡"instead of the more formal "身体清洁 (body cleaning)".

Overall layout adjustment

We adjusted the layout of options. Specifically, for items 3, 4, and 5, we placed the response option "Not applicable, he/she died at home" first, while for items 11, 13, 15, 18, 25, 29, etc., this response option was originally placed last. After discussion within the research team, to ensure consistency in questionnaire layout, we decided to place "Not applicable, he/she died at home" at the beginning of the options for all relevant items.

Details revision

For example, Items 17 and 18 are relatively complex questions that deal with infusion during the last two days of life, which are crucial for reflecting the quality of care for dying patients. Therefore, we explicitly presented the implied meanings after "Yes" and "No" in a simplified form to help family members better understand. Additionally, in Items 20 and 31, since the word "您 (you)" appeared twice in the same sentence, we added a underline to the second "您(you)" to enable respondents to answer the questionnaire more accurately.

Discussion

The translation and culture adaptation of the i-CODE questionnaire into Chinese was a complex and iterative process aimed at ensuring its validity and applicability in the Chinese context. This discussion would analyse the challenges encountered, strategies to address them, and the implications of our findings.

Challenges and strategies in cross-cultural adaptation

Linguistic and cultural differences

Similar to other cross-cultural adaptation studies [25], we faced significant linguistic and cultural differences between the English and Chinese languages. For example, certain terms and expressions in the original questionnaire did not have direct equivalents in Chinese. The term “noisy rattle” in item 14 was a particular challenge. Its translation required careful consideration to convey the intended meaning accurately. Initially, different translations were proposed, and after discussions with translators and experts, we finally settled on “呼吸时有明显的痰鸣音(喘息声)” after cognitive interviews with family members. This iterative process of translation and refinement was crucial in bridging the linguistic gap and ensuring cultural appropriateness.

Subject and terminology consistency

In the process of translation, there may be situations where the same concept is expressed in different vocabulary, which may easily confuse the respondents and affect the validity of the data. For the terminology “died/dying/death”, we chose the compromise word “离世” to run through the whole questionnaire after much discussion, in order to maintain the consistency and unity of the questionnaire. Moreover, the translation of term such as “healthcare team” also required careful consideration. We initially translated it as “医疗团队(medical team)”, but after consulting with the original author and experts, we adopted the term “healthcare team” to better reflect the comprehensive nature of the team, including non-medical members. In addition, we unified the subject of the questionnaire by changing the first person “I/my” to the second person “you/your” in items 22 and 28 to the second person “you/your” to improve the consistency and clarity of the questionnaire.

Response option ambiguity

The Likert response options also presented some difficulties. For example, the options “not sure” and “don’t know” in item 27 were not easily distinguished by some Chinese family members during the cognitive interviews. This may need further revision in the future. Nevertheless, we decided to keep these two options to maintain consistency with the original questionnaire, while being aware of the potential bias this might introduce during psychometric validation.

Strategies employed

To address these challenges, we adopted a multi-step approach. We first obtained permission from the original author and formed a multidisciplinary research team. This ensured a comprehensive understanding of the questionnaire’s content and context. We then followed an approach that combined Brislin’s Classical Back-Translation Model for initial linguistic validation and the EORTC translation guidelines for clinical relevance assurance. Throughout the process, we conducted forward and backward translations, reconciliations, and expert consultations to ensure conceptual equivalence and cultural adaptation. Cognitive interviews were also carried out to further validate the cultural appropriateness and linguistic comprehensibility of the questionnaire.

Comparison with other translations

To our knowledge, although the i-CODE questionnaire is currently available in 11 languages, there is a scarcity of published studies focusing on the translation processes of these languages. Among them, only one study on translation and validation of the German version of the i-CODE has been reported [26]. However, it primarily focuses on testing the reliability and validity of the German version for assessing the quality of care for dying patients, with limited details regarding the specific translation process.

Despite the lack of comprehensive translation process for i-CODE in other language versions, comparing our translation process with other known translations [27, 28] can still offer valuable insights. In the translation of other questionnaires, similar challenges related to linguistic and cultural differences have been commonly reported. These challenges often include finding equivalent terms and expressions, maintaining conceptual equivalence, and ensuring cultural appropriateness. In our study, we also encountered such issues, like the difficulty in translating terms like “noisy rattle” and “in the right place”. By examining how other translations have addressed comparable challenges, we can learn from their experiences and further refine our own translation process. Additionally, understanding the strategies employed by other researchers, such as the use of multidisciplinary teams, forward and backward translations, and expert consultations, can provide a broader perspective on effective translation methodologies. This comparative analysis not only enhances the quality of our current translation but also contributes to the overall body of knowledge on cross-cultural adaptation of palliative care-related questionnaires.

Implications of the findings

Anticipated impacts on quality of care

In the future, the culturally adapted Chinese version of i-CODE questionnaire will be used by the healthcare provider to conduct structured interviews or surveys with bereaved family members in clinical settings across China, such as hospitals, community, and hospice care facilities to explore the demand of dying patients and their families. The Chinese version of i-CODE questionnaire provides a standardized method for assessing the quality of care for dying patients, enabling the accurate identification of specific care challenges in local contexts, such as communication barriers between doctors and patients or unmet spiritual care needs. Moreover, the data collected using the Chinese version of i-CODE questionnaire can inform quality improvement initiatives of hospital, such as guiding the development of training programs focused on culturally sensitive symptom management.

Impact on psychometric properties

The process of cross-cultural adaptation can potentially affect the psychometric properties of the questionnaire. While our aim was to maintain the validity and reliability of the original questionnaire, some changes made during the adaptation process may introduce biases or inconsistencies. Therefore, it is important to conduct psychometric validation studies after the adaptation process to assess the impact of these changes and make further refinements if necessary.

Limitations and future directions

Limitations

This study is not without limitations regarding the methodology. First, we were not able to use the backward translators who are the native English speakers with a good command of Chinese. This may explain some differences between the original and back-translated versions. In addition, the “Snowball sampling” was used to recruit participants, which may have led to nonrandomization of the samples, resulting in participants were not diverse enough in terms of sociodemographic characteristics, which could have introduced sampling bias into the study. Lastly, we conducted the interviews online, this may have led to a tendency for younger bereaved relatives to participate in cognitive interviews, which may limit the generalizability of the findings.

Future directions

Future research will focus on conducting larger-scale psychometric validation studies to further assess the reliability and validity of the Chinese version of the i-CODE questionnaire. Additionally, exploring the experiences of a more diverse group of respondents, such as those from different regions and cultural backgrounds within China, could provide a more comprehensive understanding of the questionnaire’s applicability.

Conclusion

In this study, we translated and culturally adapted i-CODE questionnaire, and demonstrated face and content validity and acceptability of the questionnaire through cognitive interviews with bereaved family members within the hospital. Moreover, this study underscores the importance of a systematic and rigorous approach to questionnaire translation and adaptation, particularly in cross-cultural contexts. The involvement of a multidisciplinary team, including translators, clinical experts, and cultural consultants, was instrumental in addressing linguistic and cultural challenges. Additionally, cognitive interviews with family caregivers provided valuable insights into the comprehensibility and cultural appropriateness of the questionnaire, further enhancing its validity. However, limitations such as the nonrandomly sampling of participants and the reliance on online interviews may have introduced biases, which should be addressed in future research. Future directions include conducting larger-scale psychometric validation studies to assess the reliability and validity of the Chinese version of the i-CODE questionnaire comprehensively. Exploring the experiences of a more diverse group of respondents, including those from different regions and cultural backgrounds within China, will also be essential to ensure the questionnaire’s broader applicability. Overall, this study contributes to the growing body of research on cross-cultural adaptation of palliative care-related questionnaires and highlights the critical role of cultural sensitivity and methodological rigor in ensuring the effective translation and adaptation of tools for global health research.

Acknowledgements
We gratefully thank all the members of the research team for making the study progress smoothly. We would like to also thank the translators and the experts who contributed to the study. Additionally, we would like to thank all the bereaved family members for sharing their views.

Authors’ contributions

XZ contributed to the design, methodology, interview, data analysis, writing the draft of the manuscript. FC, XZ, YW and DX conducted in translation and proofreading. JZ and CRM supported the research design and participated in translation and proofreading. MM involved in the design, methodology, supervision. All the authors read and approved the final manuscript.

Funding
None.

Data availability

The data and materials can be obtained from the corresponding author of this study upon reasonable request.

Declarations

Ethics approval and consent to participate

The research was conducted in accordance with the Declaration of Helsinki and its later amendments and was approved by the Ethics Committee of the

Tohoku University Graduate School of Medicine, Sendai, Japan (ID: 2022–1-1022). Oral informed consent was obtained from all participants (bereaved family members).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

[1]Department of Palliative Nursing, Tohoku University Graduate School of Medicine, Sendai, Japan. [2]Changchun Humanities and Science College, Changchun, China. [3]School of Nursing, Sun Yat-Sen University, Guangzhou, China. [4]Division of Clinical Medicine, School of Medicine & Population Health, University of Sheffield, Sheffield, England. [5]Palliative Care Unit, University of Liverpool, Liverpool, England. [6]School of Nursing, Changchun University of Chinese Medicine, Changchun, China.

Received: 2 May 2024 Accepted: 24 April 2025

References

1. State Statistical Bureau. Bulletin of the seventh national census (No. 5)—Population age composition. 2021. http://www.stats.gov.cn/ztjc/zdtjgz/zgrkpc/dqcrkpc/ggl/202105/t20210519_1817698.html. Accessed 10 Dec 2022.
2. Outlook Newsweek. Chronicle of governance. 2021. http://www.news.cn/politics/leaders/2021-10/10/c_1127942702.htm. Accessed 10 Dec 2022.
3. Information Office of the State Council. Prevention and control of chronic diseases (scio.gov.cn).2020. http://www.scio.gov.cn/xwfbh/xwbfbh/wqfbh/42311/44583/zy44587/Document/1695361/1695361.htm. Accessed 18 Feb 2023.
4. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, Bray F. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin. 2021;71(3):209–49. https://doi.org/10.3322/caac.21660.
5. World Health Organization. World health statistics 2023: monitoring health for the SDGs, sustainable development goals, Golobal Report. https://www.who.int/publications/i/item/9789240074323 (2023). Assessed 03 Feb 2024.
6. Finkelstein EA, Bhadelia A, Goh C, Baid D, Singh R, Bhatnagar S, Connor SR. Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. J Pain Symptom Manage. 2022;63(4):e419–29. https://doi.org/10.1016/j.jpainsymman.2021.12.015.
7. Ling M, Wang X, Ma Y, Long Y. A Review of the Current State of Hospice Care in China. Curr Oncol Rep. 2020;22(10):99. https://doi.org/10.1007/s11912-020-00959-y.
8. Gong FF, Sun X, Li YN. Comparative study on the development of hospice care in different regions of China. Modern Hospital Management. 2021;05:10–3 (in Chinese).
9. Stiel S, Pastrana T, Balzer C, Elsner F, Ostgathe C, Radbruch L. Outcome assessment instruments in palliative and hospice care–a review of the literature. Support Care Cancer. 2012;20(11):2879–93. https://doi.org/10.1007/s00520-012-1415-x.
10. Ewing G, Austin L, Jones D, Grande G. Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. Palliat Med. 2018;32(5):939–49. https://doi.org/10.1177/0269216318756259.
11. Lees C, Mayland C, West A, Germaine A. Quality of end-of-life care for those who die at home: views and experiences of bereaved relatives and carers. Int J Palliat Nurs. 2014;20(2):63–7. https://doi.org/10.12968/ijpn.2014.20.2.63.
12. Burge F, Lawson B, Johnston G, Asada Y, McIntyre PF, Grunfeld E, Flowerdew G. Bereaved family member perceptions of patient-focused family-centred care during the last 30 days of life using a mortality follow-back survey: does location matter? BMC Palliat Care. 2014;13:25. https://doi.org/10.1186/1472-684X-13-25.
13. Mayland CR, Williams EM, Addington-Hall J, Cox TF, Ellershaw JE. Assessing the quality of care for dying patients from the bereaved relatives' perspective: further validation of "Evaluating care and health outcomes–for the dying." J Pain Symptom Manage. 2014;47(4):687–96. https://doi.org/10.1016/j.jpainsymman.2013.05.013.
14. Mayland CR, Gerlach C, Sigurdardottir K, Hansen MIT, Leppert W, Stachowiak A, Krajewska M, Garcia-Yanneo E, Tripodoro VA, Goldraij G, Weber M, Zambon L, Passarini JN, Saad IB, Ellershaw J, Haugen DF. Assessing quality of care for the dying from the bereaved relatives' perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure. Palliat Med. 2019;33(3):357–68. https://doi.org/10.1177/0269216318818299.
15. Mayland CR, Keetharuth AD, Mukuria C, Haugen DF. Validation of 'Care Of the Dying Evaluation'(CODE™) within an international study exploring bereaved relatives' perceptions about quality of care in the last days of life. J Pain Symptom Manage. 2022;64(1):e23–33. https://doi.org/10.1016/j.jpainsymman.2022.02.340.
16. The international collaborative for best care for the dying person. (2020) https://www.bestcareforthedying.org/code. Accessed 5 Nov 2022.
17. Han XP, Mei X, Zhang J, Zhang TT, Yin AN, Qiu F, Liu MJ. Validation of the Chinese Version of the Quality of Dying and Death Questionnaire for Family Members of ICU Patients. J Pain Symptom Manage. 2021;62(3):599–608. https://doi.org/10.1016/j.jpainsymman.2020.12.022.
18. Zhao J, You L, Tao H, Wong FKY. Validation of the Chinese version of the Care Evaluation Scale for measuring the quality of structure and process of end-of-life care from the perspective of bereaved family. BMC Palliat Care. 2021;20(1):85. https://doi.org/10.1186/s12904-021-00777-4.
19. Zhao J, Wong FKY, You L, Tao H. Validation of the Chinese Version of the Good Death Inventory for Evaluating End-of-Life Care From the Perspective of the Bereaved Family. J Pain Symptom Manage. 2019;58(3):472–80. https://doi.org/10.1016/j.jpainsymman.2019.05.014.
20. Mayland CR, Lees C, Germain A, Jack BA, Cox TF, Mason SR, West A, Ellershaw JE. Caring for those who die at home: the use and validation of 'Care Of the Dying Evaluation' (CODE) with bereaved relatives. BMJ Support Palliat Care. 2014;4(2):167–74. https://doi.org/10.1136/bmjspcare-2013-000596.
21. Brislin RW. Back-translation for cross-cultural research. J Cross-Cult Psychol. 1970;1:185–216.
22. Kuliś D, Bottomley A, Velikova G, Greimel E, Koller M. EORTC quality of life group translation procedure. (Fourth Edition). 2017. https://www.eortc.org/app/uploads/sites/2/2018/02/translation_manual_2017. Accessed 20 May 2022.
23. Ahmed N, Bestall JC, Payne SA, Noble B, Ahmedzai SH. The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs. Support Care Cancer. 2009;17(6):665–73. https://doi.org/10.1007/s00520-008-0521-2.
24. Willis GB. Cognitive interviewing: a tool for improving questionnaire design. Thousand Oaks, CA: SAGE;2011.
25. Dai Y, Johnson CE, Ding J, Chen Y, Connolly A, Wang L, Daveson BA. Cross-cultural adaptation and psychometric validation of point-of-care outcome assessment tools in Chinese palliative care clinical practice. BMC Palliat Care. 2024;23(1):89. https://doi.org/10.1186/s12904-024-01395-6.
26. Vogt A, Stiel S, Heckel M, et al. Assessment of the quality of end-of-life care: translation and validation of the German version of the "Care of the Dying Evaluation" (CODE-GER) - a questionnaire for bereaved relatives. Health Qual Life Outcomes. 2020;18(1):311. https://doi.org/10.1186/s12955-020-01473-2.
27. Sterie AC, Bernard M. Challenges in a six-phase process of questionnaire adaptation: findings from the French translation of the Integrated Palliative care Outcome Scale. BMC Palliat Care. 2019;18(1):38. https://doi.org/10.1186/s12904-019-0422-9.
28. Xie Z, Tang S, Johnson CE, Xiao L, Ding J, Huang C. Translation, cross-cultural adaptation and validation of the Chinese version of supportive and palliative care indicators tool (SPICT-CH) to identify cancer patients with palliative care needs. BMC Palliat Care. 2025;24(1):4. https://doi.org/10.1186/s12904-024-01641-x.

Publisher's Note