Care of the Dying Evaluation (CODE) questionnaire: translation and psychometric appraisal for application in Persian-speaking populations

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Abstract:

Aim and background: Palliative care provision to patients and their proxies at the very end of life is an important and explicit aspect of the human right to health. National policies and practices in the Iranian Healthcare System (INHS) do not incorporate palliative care as a core service into the routine healthcare packages. This deficiency could cause distressing experiences in a critical time for both Iranian patients and their families leading to poor outcomes in terms of their mental health and overall well-being. The "Care of the Dying Evaluation" (CODE^{TM}) questionnaire is a tool used with bereaved families and informal care givers. It consists of 42 items to assess the quality of care and the level of support provided to dying patients and their families in the last days of life. The main aim of this study was to appraise the psychometric properties of the Persian version of the CODE^{TM} (CODE-P) for application in practice and research settings within the country's socio-cultural context. An additional aim was to provide key overall findings about areas of high quality care and areas of unmet need.

Method: A forward/ backward translation procedure was performed to translate the original CODE^{TM} into Persian. The questionnaire's face and content validity was tested by a panel of experts. CODE^{TM} was completed by 280 relatives of deceased patients (from life-limiting disease) in the city of Ardabil, North West of Iran. Construct validity, internal consistency and reliability was assessed using exploratory factor analysis (EFA), Cronbach's α and spearman brown coefficient respectively.

Results: CODE^{TM} was found to have good face and content validity (mean impact score = 4.01 and content validity index (CVI) = 0.92). EFA identified five factors- health promotion; symptom management; respectful and supportive treatment; informing and participating; and discussion about treatment. These factors worked well together in terms of their construct validity (factor loadings range from 0.31 to 0.84) and internal consistency (Cronbach's Alpha coefficient = 0.91).

Conclusion: The observed psychometric properties of the CODE-P in this study support its validity and reliability for evaluating end of life care in Persian-speaking populations. Rigorous assessment of end of life care in hospitals could be an integral part of the patient-centered healthcare quality improvement endeavors. A worldwide disparity exist in the quality of end-of-life care but the challenge is more complex and impressive for the resource limited countries. Application of the CODE-P for assessment end of life care provision in the Persian-speaking context could provide a base for tailor-made evidence based interventions.

Keywords: Palliative care; End of Life Care; Health Care Providers; Hospital; Bereavement; Family Members; Psychometric appraisal; Post-bereavement survey.

Introduction:

Providing care at the very end of life for patients and their family members, facing challenges associated with a life-threatening illness, is an explicit and important aspect of the human right to health (WHO-OHCHR) (1, 2). The fundamental principles of palliative care provision to dying patients and their family members and informal care givers are to meet their physical, psychological, social and spiritual needs (3).

According to the World Health Organisation (WHO) report (2), globally, about 40 million people/year are in need of palliative care with the majority (76%) living in low and middle-income countries (LMIC) (4). It is estimated, however, that only 14% of people who need palliative care are receiving this (2) therefore an extensive unmet need exists leading to a greater burden on patients, families, hospitals and whole societies (5).

Provision of palliative care could help focus on the priorities and wishes important to patients and their families and potentially reduce unnecessary service use and costs that is especially important in resource limited countries (2). Inclusion of palliative care in routine healthcare packages represents an ethical mandate for ensuring equitable access to health care (3).

Palliative care is not provided to patients and their family members in the Iranian National Healthcare System (INHS) as a core element of routine healthcare services (6, 7). This dichotomy between science and practice heralds an important area of unmet need that could cause distressing experiences for Iranian patients and their families (8).

In order to improve quality of care at the very end-of-life, we first need to evaluate the current quality of care. Care of the Dying Evaluation" (CODE™) is a tool used with bereaved families and informal care givers (42items) that assesses the quality of care and the level of support provided to dying patients and their families in the last days of life (9). CODE™ is unique from other post-bereavement questionnaires (10) as it is based upon the best practice and principles for 'care of the dying' (11). CODE^{TM} was initially validated within the United Kingdom (9), where factor analysis identified three composite scales: environment, care, communication. Further validation on an international level involving 7 countries, identified four main factors: overall care, communication and support, trust, respect and dignity and symptom management (12).

The psychometric properties of the CODE^{TM} (9) has been assessed for use in different populations (9, 10) but not in the Persian-speaking context. Therefore, the main aim of this study was to appraise the psychometric properties of the Persian version of the CODE^{TM} (CODE-P) for application in Persian-speaking populations. A secondary aim was to provide key overall findings about areas of high quality care and areas of unmet need.

Methods:

Study design and participants: This cross-sectional study retrospectively reviewed the experiences of the family members and informal care givers of patients who died from a progressive, incurable illness in selected hospitals during the previous 12 months. Convenience sampling was used to recruit participants. Data collection was conducted (October 2020 and June 2022) by face-to-face or telephone interview or by potential participants completing an online version of CODE^{TM}. The inclusion criteria were: >=18 years old, and being a family member or informal care giver of a patient hospitalized at least for 2 days due to a progressive, incurable illness before death within specific internal surgery, hematology, infectious diseases, urology and neurology wards. Exclusion criteria were death of the next of kin as a result of COVID-19 (due to restrictions set by the study approving committee), a sudden, unexpected death (e.g., due to an accident or circumstances that resulted in a sudden death), unwillingness of the approached relatives to take part in the study or inability to provide informed consent.

Study location and data collection procedures: The study was conducted in the Ardabil province, Northwest of Iran within four hospitals (Imam Khomeini, Alavi, Fatemi, and Imam Reza) affiliated to the Ardabil University of Medical Sciences. The contact numbers and addresses of the deceased patients or their relatives were extracted from the medical records within the specified wards. A telephone call was made by the study team members to all the selected patients' next of kin for giving detailed information about the study aims and objectives and their rights in leaving the study without obligation to explain the reasons. Those who gave their verbal consent to participate in the study were provided (by post, email or social media accounts) a printed or electronic copy of an informed consent form attached to the study brochure to read and sign. The respondents were given options to self-complete the electronic version or participate in a face to face or telephone interview to provide response to the CODE-P questions.

Data collection tool and translation procedure: The study data collection tool was the Persian translated version of the "Care of the Dying Evaluation" (CODE-P) questionnaire. A standard forward/ backward translation procedure was used in keeping with the European Organisation for Research and Treatment of Cancer (EORTC)'s recommended guideline (13). CODE^{TM} questionnaire was translated into Persian by two professional translators (an English language translator and a specialist in nursing with proficiency in English language). The prepared Persian translated versions were reconciled and back translated into English by two other independent translators who were unaware of the original questionnaire. The back translated versions were compared and assessed at the next stage to produce a consensual interim version. Comparison between the proof-read back translated version and original CODE^{TM} was undertaken, with minor revisions made to ensure consistency.

Face and content validity appraisal

An expert panel was convened consisting of 15 individuals working in the fields of palliative care, health education and promotion, nursing and occupational medicine. Panel members were requested to give their opinion about the importance, relevance and clarity of each question item. Face validity was calculated by impact score (frequency of experts giving item an importance rating of 4 or 5). Content validity was assessed using the Content Validity Ratio (CVR) and Content Validity Index (CVI).CVR measures the essentiality of an item by the formula (CVR = (Ne – N / 2) / (N / 2) in which Ne is the number of panelists indicating "*importance*" of an item and N is the total number of panelists) (14). The recommended cutoff points in the Lawshe's table (15) were used to pinpoint the acceptable items based on the estimated CVR. CVI measures item relevance which was computed using the Item-level CVI (I-CVI) and the Scale-level-CVI (S-CVI). I-CVI was computed as the number of experts giving a rating of "*relevant*" or "*very relevant*" for each item divided by the total number of experts. S-CVI/Ave was the average of the I-CVI scores for all items on the scale and calculated by taking the sum of the I-CVIs divided by the total number of items (16).The panel members in addition to seven bereaved relatives were also asked to give their feedback about the CODE- P items in terms of their clarity, sensitivity, lucidity of wordings, ability to recall specific information in responding every individual item and also about the response options (17). Very minor amendments were made based on the responses and a final draft of the CODE-P was prepared for construct validity appraisal.

CODE-P construct validity appraisal

The construct validity of the CODE-P was assessed by qualitative and quantitative methods. For qualitative construct validity, five informants were asked to provide their views on consistency of the questionnaire's items regarding their adjustment with the background cultural environment. Exploratory factor analysis (EFA) was performed on the study data. The Kaiser-Meyer-Olkin (KMO) test of sampling adequacy and the Bartlett Sphericity test were conducted to assess appropriateness of the data for factor analyses. Principal Axis Factoring (PAF) method, and Principal Component Analysis (PCA), as a dimensionality-reduction method with the Varimax rotation were also conducted to recognize the latent factors in the study data.

The internal consistency was assessed by estimating the Cronbach's α coefficient (18) and its reliability by conducting split half analyses and estimating spearman brown coefficient (with values >0.70 being regarded as satisfactory) (19). The values of estimated Cronbach's Alpha coefficient above 0.90 considered to indicate excellent internal consistency, above 0.80 a good and above 0.70 an acceptable internal consistency in this study (20). All analyses were performed using the SPSS (version 25) software (21) and also STATA (version 17) (22).

Results:

Study participants and data collection:

From 1589 relatives of deceased persons in recent 12months, 663 met the inclusion criteria. Two-hundred and eighty completed the questionnaire (response rate: 42.23 %).Baseline demographic data (Table 1) showed 55.7% of the deceased patients were over 70 years old and 56.1% were male. Cerebrovascular accident and neurological disorders (stroke, brain hemorrhage, and dementia) was the main recorded cause for hospitalization (41.7 % of patients). The most common age range (40%) of the bereaved relatives of the deceased persons was 30-39 years old and 61.8%

of them were male. Most of the interviewees (63.2%) were the son or daughter to a deceased patient. The majority of the deceased patients (97.9%) identified as being Azeri. Face to face interview was conducted with 15 respondents (5.36%), telephone interview with 229 (81.78%) and electronic version of the questionnaire was sent to 36 of the deceased patients' relatives (12.86%) to complete.

PLEASE INSERT TABLE 1 HERE

CODE-P psychometric appraisal results:

Face validity: Based on the feedback received from the relatives of the deceased persons in the pilot testing phase some of the respondents might not have information about a number of the questionnaire's items therefore, "don't know'/not applicable" options were added where needed (23). The mean impact score was 4.01. Since, all the items had impact score values above the recommended cut-off point of (1.5) (24, 25) they were kept in the CODE-P (Table 2).

PLEASE INSERT TABLE 2 HERE

Content validity: The calculated CVR for the 25 of items(78.12%) were in the vicinity of acceptable range and higher than the minimum Lawshe`s recommended criterion of 0.60 (15). Seven items (Q10, Q14, Q17, Q18, Q27, Q28, and Q32) had CVR < 0.60 but they were decided to be kept for further validation in view of expert opinions. All items of the CODE-P had positive CVR in the range of 0.33-1 that reflect agreement of at least half of the panelists on importance of the items in measuring the proposed construct (26).

The estimated I-CVI for 29 items (90.62%) were above the acceptable cut-off point of 0.79 (16, 17) and in the rangeof0.73 to 1.00. The estimated CVI for Q14, Q17, and Q19 was between 0.70 - 0.79, but these items were also decided to be included in the questionnaire for further assessment after revisions. The validity of the whole questionnaire was in the vicinity of acceptable range (S-CVI/Ave= 0.92)based on the Waltz and Bausell recommendations (27) (Table 2).

Construct validity: The CODE-P's qualitative construct validity was approved by the approached panelists in terms of relevancy and consistency with the sociocultural milieu of the country.

Factor analysis

The estimated values for Kaiser-Meyer-Olkin (0.832) and Bartlett's test ($\chi 2$= 632.202; p<0.000) confirmed the suitability of the data for factor analysis. Based on the PCA with Varimax and Kaiser Rotation, the estimated eigenvalues and observed knees in the scree plot, a 5-factor solution model was adopted as the most plausible model that fitted the study data. The extracted 5-factor model explained 52.43 % of the total variance and included all core items of the CODE. The factors' labeling was done based on the proximity of the included items and review of the relevant literature (9, 28) (Table 2).

Reliability: The estimated internal consistency of the whole scale and its 5 subscales (the care received from the nurses & doctors, symptom management, respectful and supportive treatment, informing and participating, discussion about treatment)) were excellent (Cronbach's α = 0.91) for the whole scale and good or excellent for the subscales (Cronbach's α> 0.8). The exception was subscale 4 (informing and participating) although internal consistency was still satisfactory (Cronbach's α of 0.7) (Table 2).The CODE-P was also found to have high split-half reliability (r = 0.90).

Measured quality of dying care:

Among the recruited relatives of deceased patients in this study 87.0% of the respondents perceived that ‘the doctors and nurses did all they could’ to control pain. Similarly, 85.5% respondents perceived retained respiratory tract secretions were controlled. In terms of unmet need, 12.0% respondents would have found a discussion about what to expect during the dying phase to be helpful (Table 3). In terms of the five subscales, ‘symptom management’ (Q10-Q15) indicated the highest mean score (mean score: 9.39, in the range of 0–12) and ‘informing and participating’ (Q16, Q23-Q25) had the lowest mean scores (mean score: 1.26, in the range of 0 to 5) (Table 3).The estimated mean score of the whole CODE-P was 48.51 (range 0-82) (Table 3).

PLEASE INSERT TABLE 3 HERE

Discussion:

Our study findings show that CODE-P was a valid and reliable tool for assessing quality of care for the dying in a Persian-speaking context. To our knowledge, this is the first post-bereavement tool to be adapted for a Persian-speaking population. The five identified sub-scales - the care received from a HCP; symptom management; respectful and supportive treatment; informing and participating; and discussion about treatment - worked well together in terms of their internal consistency and construct validity. According to the findings, symptom control was perceived to be good whereas areas of unmet need related to communication e.g., preparation about what to expect during the dying process and information about care and treatment.

A key difference within our study relates to the fact that almost two thirds of our respondents were male and the son to the deceased. This contrasts with the majority of other post-bereavement studies were respondents are commonly female and the spouse or partner. This may imply cultural gender-specific variations in research participation willingness or caring role which is also pinpointed in other studies (29, 30).

Symptom management in this study received the highest score in keeping with perceptions about good care that align with the findings of other studies on the bereaved families and informal care givers of dying patients in the United States (31) and Sweden (32). This is while, inadequate symptom control of dying patients was reported in some research reports (33).

By way of contrast, aspects relating to communication received the lowest scores, indicating unmet needs in this area. Previous research (33) has also highlighted this unmet need. This may relate to the global importance of apposite communication of HCPs with the bereaved relatives about dying patients' circumstances (34) or HCPs' low level of self-confidence or actual competency in disclosing bad news and providing the required support to dying patients' family members (35, 36).

Patients and their family members' awareness about basic healthcare rights might impact on their level of satisfaction with the provided care in healthcare settings. This may lead to lowering of expectations among healthcare customers and in consequent a higher degree of their satisfaction. In a previous study (*of whom*?) (37), 40 % of the participants were dissatisfied about not being involved in the therapeutic decision making despite feeling that it is their right to be involved. This is an indication of the impact basic knowledge level about human rights and contested beliefs may pose on people's overall expectations from HCPs and with the same token about end-of-life care and good death (38). The study participants' perceptions about the obtained care received higher scores than anticipated. This may relate to lower expectations of the study attendees from the health system. While, knowledge of the study attendees about their healthcare rights (as the relatives of a deceased patients) was not probed in this research, its assessment could be beneficial in future studies to prevent misleading conclusions.

Receipt of insufficient information about the patient's condition, his/her disease circumstances, prognosis and the decided treatment plan was one of the most common complaints of relatives in our study leading to their confusion and indecision. Provision of ample information about conditions of a critically ill patients to their relatives or accompanying friends was suggested to be an important measure to lower their anxieties (39) which is not always considered by HCPs (40). Such a deficit was not uncommon in the developing and less developed countries (39).

A high degree of satisfaction with palliative care provision in the developed world was reported in relation to the management of the patients' symptoms and comfort, health information provision, family support and psychological care (41). This study findings however, indicated good perceptions of symptom control but poor perceptions about healthcare communication. The observed discrepancy need to be further investigated in future studies in terms of consequences and root causes of the organizational failure in providing sensible health care.

Memorizing and speaking about emotional experiences bereaved relatives or friends had in relation to a deceased patient might be an overwhelming challenge (38). Some of the recruited participants in this study were willingly happy to discuss about their experiences but a number of approached individuals became upset and angry due to recalling the painful memories or unpleasant feeling they had in relation to the received or undelivered healthcare.

Integration of palliative care into routine healthcare packages in hospitals is an ethical and human rights mandate for health systems' policy makers. However, due to various reasons among them lack of authentic courage and commitment to values of fidelity and accountability in healthcare provision, there are still unmet needs for palliative care in many countries of the worlds.

Limitations: The study findings indicated socio-cultural adaptability and applicability of the CODE-P in a traditionally family-centered society however, the results warrant to be interpreted by caution due to several reasons. Probability of data collection bias because of using inconsistent data collection method/instrument for some of the study attendees (i.e. face to face interview, telephone interviews or application of an electronic version of the scale) might cast shadow on the study results (42, 43). Some deceased patients had several caregivers in the last days of their lives, and therefore a number of the participants stated that they are not sure about the type and quality of care provided to their patient in different shift times. Such an ambiguity about the provided healthcare was reported in other studies (44). Thus, in an inherently family-centered society where involvement of all close family members in providing care to an end stage patient is expected, possible examination of the several members' cumulative perceptions about the quality of provided care is recommended in future studies.

The long period of time (2-12 months) that was determined for interviewing the bereaved relatives after death of their patients in this study while being in accord with the previous studies, had potential to pose recall bias and be a source of uncertainty.

All effort were made in this study to prevent the respondents' fatigue in answering the questions. However, its potential impacts on the quality of responses (45) should not be ruled out completely.

Conclusion:

The needs of Patients approaching the very end-of-life and their family members represent important, but often overlooked, subgroups of healthcare recipients. Therefore, a global unmet need exists that heralds prompt attention to ensure an equitable healthcare provision for all. Additionally, addressing the current disparities in healthcare settings is more considerable and complex for people within LMIC. Rigorous assessment of end of life care in hospitals could be an integral part of the patient-centered healthcare quality improvement endeavors. Application of the CODE-P for assessment of the end of life care provision in the Persian-speaking context could provide an evidence-base for this quality improvement work and tailored interventions. Further expansion of cross-cultural testing of CODE-P within different socio-cultural and organizational settings, would help provide accountability and improvements across healthcare systems.

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