Psychometric Properties of End-of-Life Caregiving Experience Appraisal Scale: Iranian Critical Care Nurses

Abstract

Background: Healthcare providers should be able to provide good quality end of life care. A tool to evaluate the positive and negative consequences of caring for dying patients is warranted.

Aim: The aim of this study was to evaluate the psychometric properties of the Persian version of the End-of-life Caregiving Experience Appraisal Scale (EOLCAS).

Methods: This research was conducted in two phases. Phase I: The World Health Organization Protocol of forward-backward translation and an expert panel in order to determine face and content validity. Phase II: Survey development with 310 nurses who worked in critical care units, construct validity (construct, convergent and divergent validity), internal consistency (Average inter-item correlation, Cronbach's alpha and Omega McDonald's) and construct reliability were evaluated.

Results: The exploratory factor analysis showed that the present scale has four factors: *Negative Physical-emotional and social consequences, transcendental communication, information deficits,* and *future rumination* which explained 83.92% of the overall extracted variance. Convergent and divergent validity was confirmed for all factors. The internal consistency and construct reliability were acceptable.

Conclusion: The scale has a multidimensional concept that is sufficiently reliable and the use of the scale would be helpful in measuring consequences of caring for dying patients.

Relevance to clinical practice: This scale makes a significant contribution in that it helps in the recognition of positive and negative consequences for critical care nurses' caring for dying patients.

Key words: Psychometrics, Terminal Care, Critical Care Nursing, Iran.

BACKGROUND

Death is an expected, important and an inevitable event in the nursing profession. This is especially the case in critical care units, elderly nursing care centers and other units providing end-of-life care services (Issazadegan, Soleimani, & Ashrafzadeh, 2014; Kisorio & Langley, 2016). Many patients are admitted to critical care units just before the end of their lives in order to receive life-saving and body-function restoring measures, however because of the inevitable deterioration in many patients' conditions, the role of nurses may change from life-sustaining activities to end-of-life nursing care (Gozalo et al., 2011; Jang, Park, Kim, & Chang, 2018). Nurses may express various reactions when dealing with death and the caring of dying patients. In other words, daily exposure to death may impact nurses emotionally and physically; according to different studies, repeatedly facing death and the caring of dying patients have been accompanied by fear and anxiety, depression, emotional fatigue, occupational stress and even burn out (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Lopera Betancur, 2015).

Nurses are more affected when they encounter the death of a particular patient such as the death of a child, friend or colleague, as well as the deaths of victims of disasters (Goudarzian, Bagheri Nesami, Zamani, Nasiri, & Beik, 2017; Hamid Sharif Nia, Lehto, Ebadi, & Peyrovi, 2016). But we should keep in mind that death and end-of-life care can affect nurses both positively and negatively (Lopera Betancur, 2015).

Dunn, Otten, and Stephens (2005) suggested that a positive attitude about caring for dying patients among registered nurses so that those who had spent more time with terminally ill patients reported more positive attitudes (Dunn et al., 2005), however, it was also shown that negative attitudes about caring of dying patients existed amongst nursing students in Iran (Jafari et al. (2015). There are studies who mention the positive aspect of providing End-Of-

Life Care (EOLC) like personal growth, improving nurses' capacity to cope and talk about death and positive attitudes toward caring for dying patients and their families (Abu Hasheesh, Al-Sayed AboZeid, Goda El-Zaid, & Alhujaili, 2014; McAndrew & Leske, 2015; Peters et al., 2013; Rotich & Agbehiadzie, 2016).

Jang et al. (2018) in a qualitative study have pointed out one of the positive consequences of the care of dying patients in ICU with a nurse participant stating "I do not think death is the end of life, I think that life is like the driving force and death is something that everyone must experience without any exception, so death is also an extension of life in the end" (Jang et al., 2018). The results of McAndrew and Leske (2015) study revealed another positive EOL experiences among nurses and physicians in intensive care units as achieving balance during EOL decision making (McAndrew & Leske 2015).

Obviously, investigating the consequences of caring for dying patients is integral for nurses who worked in critical care units because of the daily encountering of patient death. At this time, there is no validated instrument, which can assess inclusively all positive and negative consequences of providing EOLC on critical care nurses in Persian language, so development of such a tool seemed necessary.

In reviewing existing resources, there is a 32 item tool to assess the negative and positive effects of care for dying patients specifically for nurses entitled "End-of-life Caregiving Experience Appraisal Scale", which is designed by Lee et al. (2010). To design this tool, the first step is, to scale the domains which were derived from a systematic review of 35 relevant studies. Its content validity was examined with both nurse scholars and clinicians using a content validity index. In order to determine construct validity, factor analysis was used based on the views of 175 nurses who provided care for dying patients.

Considering that this tool has not been translated into any language yet, this study was designed with the aim of determining the psychometric properties of the Persian version of "End-of-life Caregiving Experience Appraisal Scale" (EOLCAS). By using the results of this study, access to a tool to facilitate the understanding of the consequences of caring for dying patients was provided. This could be effective in planning and improving the quality of care for dying patients, as well as providing the necessary support for nurses working in this field.

METHOD

Overview

Evaluation of "End-of-life Caregiving Experience Appraisal Scale" took place in two phases to test psychometrics and the feasibility of the scale.

Phase I

Written permission for the use of the EOLCAS was obtained from the developer of the scale, Professor Juhe Lee. The World Health Organization protocol of forward-backward translation technique was used for translating the scale from English into Persian (World Health Organization, 2016). Two English-Persian translators were invited to independently translate the EOLCAS. An expert panel, consisting of some of this paper's authors as well as two professional translators, assessed and unified the two translations and constructed a single Persian translation of EOLCAS. Thereafter, a Persian-English translator was asked to back-translate the Persian EOLCAS into English. This English version of the EOLCAS was sent to Professor Lee, for confirmation of the correctness of translations and confirming the similarity of the achieved English EOLCAS with its original. All comments are included in the final version of the scale.

Face Validity

At this stage, the scale was given to fifteen nurses who worked in a critical care unit. They were asked to comment on the appropriateness of the appearance, degree of clarity and

ambiguity of the selected words and the rationality of the sequence of the items in order to achieve the goals of the scale. The viewpoints of this group were included in the final version.

Content Validity

Quantitative content validity was assessed by calculating the Content Validity Ratio (CVR) and Content Validity Index (CVI) for the items. Fifteen nursing specialists (were used) for face validity, and asked to rate the essentiality of the EOLCAS items on a three-point scale as follows: Not essential: 1; Useful but not essential: 2; and Essential: 3 (Cook & Beckman, 2006; H. Sharif Nia et al., 2017). The CVR was calculated using the following formula: CVR $= (n_e - (N/2)) / (N/2)$. In this formula, N and n_e are respectively equal to the total number of experts and the number of experts who rate the intended item as 'Essential'. When the number of panelists is fifteen, the minimum acceptable CVR is equal to .49 (Lawshe, 1975). These fifteen nurses were excluded from the main sample (310 nurses).

CVI shows the degree to which the items of the intended scale is relevant and CVI can be calculated for each item of the scale (Item-level or I-CVI) and also for all of the items (Scale-level or S-CVI). Thus, we asked the same fifteen panelists to rate the relevance of the EOLCAS items on a four-point scale from 1 to 4. For instance, the four points for rating the relevance of the items were 'Not relevant, 'Somewhat relevant', 'Quite relevant', and 'Highly relevant'. They were scored as 1, 2, 3, and 4, respectively. The CVI of each item was calculated by dividing the number of panelists who had rated that item as 3 or 4 by the total number of the panelists. Jay Lynn, Surya Das, Hallquist, and William (2006) noted that when the number of panelists is equal to fifteen, the items which acquire an I-CVI value of .79 or greater are considered appropriate.

Phase II

Survey Development & Construct Validity & Reliability

Consistent with this study's aim to provide an efficient, reliable and valid tool for collecting data about the End-of-life Caregiving Experience we wanted to create a survey that was straightforward to understand and practical to administer while maximizing the usefulness of the data collected with it.

This survey was conducted on 310 nurses who worked in critical care units (ICU, CCU, and an Emergency unit) at six hospitals under the supervision of Qazvin University of Medical sciences, Iran, from February to June 2017. Participants were entered to the study using convenience-sampling method. MacCallum, Widaman, Zhang, and Hong (1999), recommended that the sample size should be at least 200 cases for psychometric studies. The nurses met the following inclusion criteria: (i) able to read and write Persian, (ii) no co-morbid psychiatric problems (e.g. schizophrenia, post-traumatic stress or other diagnosed anxiety disorder, dementia, major depressive disorder) and (iii) have at least 6 months experience in a critical care unit. The rationale for excluding nurses who reported a history of clinical depression and/or anxiety disorders was to ensure that nurses were free of psychiatric impairment. Nurses were also excluded if they self-reported potential confounding concurrent conditions such as drug or alcohol abuse or addiction. All of the participants completed two questionnaires: 1) Basic questions regarding Demographic and work related variables with 7items. 2) The End-of-life Caregiving Experience Appraisal Scale (EOLCAS) with 32 items. Data were collected in a single stage, by a paper-and-pencil method. Participants provided informed consent and deposited completed questionnaires into a closed box. The institutional ethical review, approved the research prior to implementation.

Construct Validity

The Construct validity of the scale was evaluated using Maximum Likelihood Exploratory Factor Analysis (MLEFA) with varimax rotation. In the first step, the latent factors were extracted based on Horn's Parallel Analysis (Çokluk & Koçak, 2016). Confidence intervals (CIs) were estimated for each eigenvalue based on CI 95 width (z: 1.96), each observed eigenvalue, and the sample size (n) (Larsen & Warne, 2010). The test of sampling adequacy (Kaiser-Meyer-Olkin) and the Bartlett test were implemented. The presence of a single item in the factor based on the CV = $5.152 \div \sqrt{(n-2)}$ formula (Fok, 2011) was estimated to be approximately 0.3 (in the present formula, the CV is the number of extractable factors and n is the sample size of the study). According to the three indicator rule, at least three items must exist for each factor (Munro, 2005). Through the next step, the extracted factors were evaluated by Confirmatory Factor Analysis (CFA) and goodness of fit indexes: the acceptable level of Parsimonious Normed Fit Index (PNFI), Parsimonious Comparative Fit Index (PCFI), Adjusted Goodness of Fit Index (AGFI) indices (> .5), Comparative of Fit Index (CFI), Incremental Fit Index (IFI) (> .9), Root Mean Square Error of Approximation (RMSEA): > .08 and Minimum Discrepancy Function by Degrees of Freedom divided (CMIN/DF) < 3 good (Pahlevan Sharif & Sharif Nia, 2018).

Finally in the second-order CFA, it is assumed that the extracted factors in the first stage are the reflections of another level of conception by their own and can show a more general concept on secondary and higher levels (Gatignon, 2013). Therefore, after performing first-order CFA, a second-order CFA was implemented.

Convergent & Divergent Validity

Convergent and divergent validity of the scale was evaluated using the average Variance Extracted (AVE), Maximum Shared Squared Variance (MSV) and Average Shared Square Variance (ASV) (Fornell & Larcker, 1981). For the existence of convergent validity, the

AVE must be more than .5 and for confirming the divergent validity, MSV and ASV should be less than AVE (Ahadzadeh, Sharif, Ong, & Khong, 2015; Hair Jr, Anderson, Tatham, & Black, 1995).

Reliability

In order to assess the internal consistency of EOLCAS, Average Inter-Item Correlation (AIC), Cronbach's alpha and Omega McDonald's were estimated (Javali, Gudaganavar, & Raj, 2011). The internal consistency of the scale was considered to be appropriate if it was greater than 0.7 (Mayers, 2013). Finally, the Construct Reliability (CR) was calculated (Munro, 2005). In fact, CR was considered as an alternative to Cronbach's alpha coefficient in the analysis of the structural equation model. In the present study, CR greater than 0.7 was considered to be acceptable (Wang, 2010).

Normal distribution, Outliers, and Missing data

The Univariate and Multivariate distribution of data was investigated for the distribution of normal data separately by Skewness (± 3) and Kurtosis (± 7). The existence of multivariate outlier was assessed by Mahalanobis d-squared ($p < .001$) and multivariate normality by Mardia coefficient of multivariate kurtosis (greater than 8) (Wang, 2010). The missing data was evaluated using multiple imputation, then replaced by the average participants response (Sterne et al., 2009). All of statistic procedures were calculated by SPSS- AMOS$_{25}$ and JASP$_{0.9.0.1}$.

Ethical approval

This study was approved by the Ethics Committee of Mazandaran University of Medical Sciences (Code: IR.QUMS.REC.1395.38), Sari, Iran. Nurses were informed about the study objectives and procedures. Moreover, they were assured that participation was voluntary. In addition we obtained written informed consent from each participant. All participants were assured that the study finding would be reported and published anonymously.

RESULTS

Phase I

Face & content validity

Regarding face validity, the results showed all items of the scale are appropriate, clear, and straightforward to use. The results of CVI, demonstrated that all items gained an index higher than 0.79 and were identified as appropriate without any need to be re-reviewed in the final version. Item No. 16 "*I want to deny my role as a caregiver*" was evaluated as an unacceptable item because of CVI =0.60. Also regarding the CVR results of the scale, content validity ratio of all items was greater than the minimum value of (0.49) (according to the evaluation of 15 specialists) in the Lawshe table.

Phase II

Survey Development & Construct validity & Reliability

Based on the inclusion criteria, 60 nurses were excluded (clinical depression [n = 51], addiction [n = 9]). Subsequently, 310 nurses met the criteria for inclusion in the study with response rate of 91.17%.The average age of the participants was 32.35 (SD=5.51) years. The majority of participants were women (84.5%) with a bachelor in nursing degree (87.4%) and married (63.8%). The results of MLEFA were presented in Table 1. The KMO was .913 and Bartlett's test was 3106.58, *p*< .0001. Parallel analysis indicated four factors based on the random explained common variance including: *Negative Physical-emotional and social consequences, transcendental communication, information deficits, and future rumination* (indicated in Table 1) with eigenvalues of 6.95, 3.32, 2.95, and 2.84 respectively and this explained 83.924% of the total common variance.

[Insert Table 1]

Next, the factor structure obtained with MLEFA was assessed and validated using maximum likelihood CFA. According to the results, the goodness of fit indexes of the model confirmed the appropriateness of the first order CFA model ((χ^2 (111) = 225.85, $p<$ .0001, AGFI= .885, PCFI= .786, PNFI = .759, IFI = .963, CFI = .963, RMSEA [90 %Confidence Interval [CI]) = .058 (.047 to .069)]. According to the final model of factor structure, the EOLCAS, measurement errors items four and five (e5 and e4) and 14 and 13 (e11 and e9) were correlated.

After reviewing the first-order CFA model of EOLCAS, the correlation between the constructs and the identification of the subscales to assess the concept of whether all factors are placed in the general concept of EOLCAS by structural equation modeling. Figure 1 shows the second order CFA. The factor loads were significant for all items ($p<$ .0001) greater than .3. CFA was conducted to confirm and validate the factor structure obtained from EFA. The results showed that the initial four factor measurement model was found to be a good fit, as evidenced by goodness of fit indices (χ^2(112)= 218.23, $p <$ .0001, AGFI= .893, PCFI= .795, PNFI = .767, IFI = .966, CFI = .965, RMSEA (%90 Confidence Interval [CI])= .055 (.045 to .068) and significant factor loadings greater than .5.

[Insert figure 1]

[Insert figure 2]

According to the findings, factors AVE (.637, .457, .619, and .615 respectively) was greater than MSV (.460, .457, .460, and .615 respectively) and ASV (.335, .168, .301, and .171 respectively). Therefore, the considered structure has an appropriate convergent and divergent validity. In addition, internal consistency (Table 1) and CR (.932, .765, .862, and .750 respectively) of the EOLCAS in four extracted factors in the present study was estimated to be desirable (> .7).

DISCUSSION

The results of the present study demonstrate that the EOLCAS includes four distinct and stable factors; I. *Negative Physical-emotional and social consequences. II Transcendental communication, III. Information deficits, and IV. Future rumination.* This, explain 83.9% of the variance. Lee et al. (2010) extracted four factors with 53.47% variance (*Physical suffering, Burden, Maturation and Social support pursuit*) that was not similar to our study due to factor names and number of items. It should be noted that the present study is the first study to validate this tool in the Persian language.

Negative factors included *Negative Physical-emotional and social consequences, Information deficits, and Future rumination*, which were negatively worded. As can be seen by the Cronbach alpha coefficients the findings indicate that nurses are constantly subjected to various levels of physical and psychosocial stress caused by the caring for dying patients. Also, recalling the death of past patients and the fear of death in current patients makes psychological problems more likely among nurses (Hebert & Schulz, 2006). *Transcendental communication* was considered a positive factor in this instrument. Pinquart claimed that nurses behave differently toward these patients due to values and cultures (Pinquart & Sörensen, 2005). The feeling of kindness in dealing with these patients and the sense of responsibility in trying to improve the quality of patient's life are of ideal behavior models. The results of model fitting were evaluated for all appropriate indices and all factor loads were above 0.5 indicating the existence of minimum acceptable factor load. Therefore, according to the results of confirmatory factor analysis, the observed indices were confirmed and all fitness indicators enjoyed a suitable standard level. To the best of knowledge of the authors, this was the first time CFA was measured in this type of study.

According to the final model of the EOLCAS, a relationship exists between the measurement error of item 4 (I have limited time for myself while caring for the patient), and 5 (I have

limited social relationships) and also between 13 (I feel good that I can do something for the patient) and 14 (I have a better relationship with other family). When the items are not properly known or because of the conceptual similarity of the sentences the measure errors may occur. As the concept of these four terms indicate, both items of 4 and 5 contain a constricted concept and items 13 and 14 have a transcendental concept which can instill the same meaning in participants. To access a more accurate structural equation model, second order confirmation factor analysis was used. The aim of this approach is to achieve a more meaningful method of data, assuming that the latent variables are caused by one or more factors of higher order in the common variance and the construct contains two levels (Gatignon, 2013). In fact, first-level structures do not fully act as independent variables, and the correlation between themselves, reflects the existence of a more general structure at the secondary conceptual level. The most appropriate approach for examining this structure is the structural equation model, because it can identify the first-level structures that have been distributed as latent variables (J.F. Hair, Black, Babin, & Anderson, 2013). The results of the present study showed that the items of the EOLCAS enjoy an appropriate convergent and divergent validity in its final model. In 1995, Hair states that the convergent validity exists when the objects of the structure are close to each other and share a large variance together. On the other hand, it has been stated that divergent validity exists when the items of the considered structure or the latent extracted factors are completely separate from each other (J.F Hair, Anderson, Tatham, & Black, 1995). In the clearer sense, the appropriate convergent validity would not be possible if the latent factors are not well explained by the extracted clauses and were are not sufficiently correlated (Fornell & Larcker, 1981).

The internal consistency of the EOLCAS was acceptable by AIC, Cronbach's alpha and Omega-McDonald's. The high level of Cronbach's alpha signifies the internal consistency suitability of the scale and the correlation between the items (H. Sharif Nia et al., 2014). In

the study by Lee it has been stated that the total Cronbach's alpha coefficient is .84 (Lee et al., 2010). The AIC of the items in the factors should be ranged between .2-.4, while ideals in the range .1-.5 are acceptable. According to the finding, AIC of the factors were greater than .4 therefore the factors had AIC$_S$ acceptable. In the present study also, CR was at a high level. One of the important attributes of CR estimation over Cronbach's alpha is that it is not affected by the number of scale items and obtained structure and is depended on the actual amount of factor load of each item on the latent variable (Vinzi, Chin, Henseler, & Wang, 2010). The CR value of the questionnaire was calculated in this study for the first time.

Limitations and suggestion

In the present study, there were some limitations. The researchers of this study have ensured that the forward–backward translation method was performed at a high standard and the original author of the scale confirmed the accuracy of the translation. Notwithstanding this, there is always a potential difficulty in using a scale which was originally designed for a different population. Cultural differences and language nuances may not be translatable, and test users would be advised to be cognizant of this potential issue. Factor naming was implemented according to the researchers' choice. Personal attitude of nurses at taking care of these patients, can be influenced by culture and values (Pinquart & Sörensen, 2005). The lack of similar studies in terms of the type of statistical population led to difficulty with compartmentalizing of the study. Therefore, we recommend that more detailed studies should be conducted to earn dependable results by other investigators. Future validation studies with samples from different populations and also longitudinal designs are suggested to verify the findings of this study. Also, since Iranian populations reside all over the world, testing of the tool on Iranians in Europe, Asia, and the United States would be beneficial to determine its generalizability to all Iranian diaspora.

Implications for Practice

It is clear from this study the importance of understanding and contributing to self-care with professionals who are working directly with patients who are inevitably close to the end of their life. This scale, which is the first in the Persian language, makes a significant contribution which helps to recognize nurses and other medical professionals who may be experiencing trauma or difficulty related to dealing with end of life caring. Ensuring direct and vicarious trauma is acknowledged and appropriately treated is vital for a ensuring a healthy nursing profession especially with regards to end of life care.

Conclusion

The results of this study demonstrate that the EOLCAS enjoys sufficient validity and Reliability. A significant percentage of variance can be explained according to Iran's cultural context. Considering the importance of comprehensive approach of patients in health care centers, the existence of such a tool can help to accurately measure nurses' experience in end-stage patient care, and thereby improving the quality of care delivered and quality of patient's life.

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WHAT IS KNOWN ABOUT THIS TOPIC?

• Investigating the effects and consequences of caring for dying patients is especially important for critical care nurses.

• There are currently a number of tools that mainly focused on the negative and unpleasant outcomes of this phenomenon.

WHAT THIS PAPER ADDS?

• A tool to assess the negative and positive consequences of caring for dying patients.

• The Persian version of EOLCAS is sufficiently valid and reliable; use of the scale would be helpful to assess negative and positive consequences of caring for dying patients.

• Validation of this questionnaire in other languages and nations is necessary.

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