Commentary

Adapting and Using the Quality of Dying and Death Questionnaire

Palliative care (PC) offers support for patients and families from the diagnosis of an incurable disease through to death and the aftermath. Developing relevant quality indicators is essential to demonstrate, compare, and optimize the success of end-of-life care domain in PC.[1] Multiple tools seek to assess the quality of care at the end of life and the quality of dying and death (QODD).[2] However, assessing these can be challenging because of declining health toward the end of life, the difficulty of identifying people who may be in the dying phase, and the sensitivity of involving family members in quality assessment at this time. In addition, development and validation of new tools is costly and time-consuming. Thus, research might be more productively evaluate, improve, and adapt existing tools rather than developing new ones. Such kind of research based on the QODD instrument has been done before where the reliability and validity of a clinician measure of the pediatric intensive care unit (ICU)-QODD-20 in the pediatric intensive care setting were studied.[3]

The application of PC and hospice care to newborns in the neonatal ICU (NICU) has been slowly evident through peer-reviewed publication for over 30 years now.[4] Neonatologists have long managed the entirety of many newborns' short lives, given the relatively high mortality rates associated with prematurity and birth defects, but their ability or willingness to comprehensively address the continuum of interdisciplinary palliative, end-of-life, and bereavement care has varied widely. While neonatology service capacity has grown worldwide during this time, so has attention to pediatric PC generally and neonatal–perinatal PC specifically. Improvements have occurred in family-centered care, communication, pain assessment and management, and bereavement. There remains a need to integrate PC with intensive care rather than await its application solely at the terminal phase of a young infant's life – when she/he is imminently dying.[5] There are also studies looking into applications of integrating neonatal PC into fetal diagnostic management, the developing era of genomic medicine, and the expanding research into PC models and practices in the NICU.[6] In this context, the present research article "*Translation, cultural and age-related adaptation and psychometric properties of Persian version of 'QODD' in nurses working in NICU*" is apt and raises many important issues on adapting and using the QODD Questionnaire.[7]

The QODD is an instrument for assessing the quality of dying and death, and there are few versions of it. The first version of this instrument is designed to be interviewer-administered to a significant other of a patient (who died in an outpatient or hospice setting).[8] The second version of the instrument containing 14 items was adapted for use by nurses in the ICU.[9] Another later version of this instrument is designed for self-administration by a significant other (family member and/or friend) of a patient who died in a hospital or ICU setting.[10] A similar, later version of this instrument, is designed for self-administration by a health-care professional who cared for a patient who died in a hospital or ICU setting.[2]

Let us now go through into the broad constructs of a generic questionnaire development and translation processes. To construct a new questionnaire,[11] several issues should be considered, such as:

- Identifying the dimensionality of the construct, for example, unidimensional or multidimensional; is there a need for subscales to assess the different components of the construct, and are all the dimensions equally important to assign weightage to the questions
- Determining the format in which the questionnaire will be administered, for example, self-administered or administered by a research/clinical staff, the cognitive capability of the respondents, etc.
- Determining the item format, for example, open ended or close ended. If close-ended items are to be used, should multiple-choice, Likert-type scales, true/false, or other close-ended formats be used? How many response options should be available? If a Likert-type scale is to be adopted, what scale anchors are to be used to indicate the degree of agreement (e.g., strongly agree, agree, neither, disagree, and strongly degree), frequency of an event (e.g., almost never, once in a while, sometimes, often, and almost always), or other varying options? To make use of participants' responses for subsequent statistical analyses, researchers should keep in mind that items should be scaled to generate enough variance among the intended respondents
- Item development, for example, simple, short, and written in language familiar to the target respondents, consistent perspective across items, whether to use reverse-scored items or not. Furthermore, the questionnaire should contain enough items to measure the construct of interest, but not be so long that respondents experience fatigue or loss of motivation in completing the questionnaire. This might need review, reduction, and revision of initial pool of items in later versions
- Preliminary pilot testing on a small sample (about 30–50) of respondents to get a rough idea about the feasibility of using the questionnaire. The questionnaire items should be revised on reviewing the results of the preliminary pilot testing. This process may be repeated a few times before finalizing the final draft of the questionnaire.

However, to translate a preexisting questionnaire[12,13] into a different language, the following issues need to be addressed as follows:

- The initial translation from the original language to the target language (forward translation). It should be made by at least two independent translators, preferably, having the target language as their mother tongue. Among the two translators, only one should be aware of the concepts the questionnaire unlike the other so that subtle differences in the original questionnaire may be detected
- The initial translation should be independently back translated into the original language by at least two independent translators, preferably translating into their mother language, and who are not aware of the intended concepts the measures to ensure the accuracy of the translation
- Constituting an expert committee is suggested to produce the prefinal version of the translation to decide upon the semantic, idiomatic, experiential, and conceptual equivalence of the translated version
- Preliminary pilot testing of the prefinal version of the translated questionnaire on a small sample (about 30–50) of the intended respondents. After completing the translated questionnaire, the respondent is asked for feedback. These processes may be repeated a few times to finalize the final translated version of the questionnaire.

The next steps are directed at the validating of the questionnaire, involving:

- Initial validation through pilot testing among a large sample of intended respondents
- Reliability testing through measures such as internal consistency, test–retest reliability, and inter-rater reliability
- Measuring internal consistency using Cronbach's alpha
- Testing for test–retest reliability using Pearson's product-moment correlation coefficient (Pearson's r) or the intra-class correlation coefficient
- Inter-rater reliability using the kappa statistic
- Establishing content validity and construct validity.

The authors in this article have worked on a hybrid version of the methodologies mentioned above involving focus groups of respondents.[14] They have tried to be thorough in considering the issues relating to the format of the original QODD questionnaire and the meaning and appropriateness of the items, especially in a novel health-care facility (NICU) in a cross-cultural setting. The pilot testing and subsequent validation stage were crucial to ensure that the questionnaire is psychometrically sound.

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