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The Development of a Patient-Reported Outcome Measure for Geriatric Care: The Older Persons and Informal Caregivers Survey Short Form (TOPICS-SF)

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ABSTRACT

Background: The Older Persons and Informal Caregivers Minimum Data Set (TOPICS-MDS) is a standardized data set that was developed to evaluate the quality of multidimensional geriatric care. There is an inherent need to reduce the number of TOPICS-MDS survey items to core outcomes to allow it to be more easily applied as a patient-reported outcome measure in clinical settings. **Objectives:** To create a TOPICS-short form (TOPICS-SF) and examine its validity. **Methods:** Data in the TOPICS-MDS from persons aged 65 years and older in the Netherlands were used for the following analyses. Multiple linear regression analyses were performed to select the items and to derive domain weights of TOPICS-SF. A priori hypotheses were made on the basis of psychometric properties of the full-length TOPICS-MDS preference-weighted score (TOPICS-CEP). The validity of TOPICS-SF was evaluated by 1) examining the meta-correlation of the TOPICS-SF score with TOPICS-CEP and two quality-of-life measures, that is, the Cantril Ladder score and the EuroQol five-dimensional

questionnaire utility index, and 2) performing mixed multiple regression of TOPICS-SF scores across key sociodemographic characteristics. **Results:** TOPICS-SF scores were strongly correlated with the TOPICS-CEP ($r = 0.96$) and had stronger correlation with the EuroQol five-dimensional questionnaire utility index compared with the Cantril Ladder ($r = 0.61$ and 0.38 , respectively). TOPICS-SF scores were higher among older persons who were married, living independently, and having higher levels of education. **Conclusions:** We have developed the 22-item TOPICS-SF and demonstrated its validity, supporting its use as a patient-reported outcome measure in geriatric care.

Keywords: geriatrics, patient-reported outcomes, short form, validation.

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Introduction

Aging populations demand well-organized and integrated health care. Providing high-quality health care for older populations is a unique challenge, because it involves a multidimensional approach addressing physical health, functional ability, and cognitive functioning, as well as emotional well-being and social circumstances to meet the individual expectation of each older person [1,2]. With this backdrop, The Older Persons and Informal Caregivers Survey Minimum Data Set (TOPICS-MDS; www.topics-mds.eu) was developed to aid health care professionals in evaluating quality of geriatric care by measuring health-related quality of life (HRQOL) [3]. Specifically, in TOPICS-MDS, HRQOL is derived by summarizing multiple outcome measures into a single preference-weighted summary score; this summary score has been previously referred to as TOPICS-Composite End Point (TOPICS-CEP) [4]. The preference weight of each domain in TOPICS-CEP was determined on the basis of the priorities of older persons in the Netherlands using a vignette study [4]. Thus, TOPICS-CEP represents HRQOL from the perspective of older

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Conflicts of interest: No portion of this article has been presented and/or published previously.

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persons themselves. TOPICS-CEP has been validated for its use in older populations [5], underlining its potential use as a patient-reported outcome (PRO) in geriatric care. Because PROs aim to assess whether the expectations of older persons are met at both individual and aggregate levels (e.g., hospital performance indicators), TOPICS-CEP can be seen as a type of PRO.

TOPICS-MDS and the corresponding TOPICS-CEP are based on 42 data points, which cover eight domains of health and well-being [4]. Nevertheless, in clinical settings where time and availability of personnel are often scarce, such as in the hospital, a shorter and more concise instrument is needed [6,7]. Therefore, the first aim of this study was to reduce TOPICS-MDS to its most substantial items in a short form (TOPICS-SF). We further defined a set of criteria that should be met by the shortened form, because previous studies have suggested that some items within activities of daily living (ADL) and instrumental activities of daily living (IADL) scales in the original TOPICS-CEP were affected by response bias [8,9].

Nevertheless, before adoption of the TOPICS-SF, it is critical to confirm that the instrument is valid. Thus, our second aim was to assess the validity of the TOPICS-SF by evaluating how well its preference-weighted score in measuring HRQOL related to the original TOPICS-CEP.

Methods

Data Source

TOPICS-MDS is a public data repository designed to capture essential information on the physical and mental well-being of older persons and informal caregivers in the Netherlands. A detailed description of TOPICS-MDS has been presented elsewhere [3]. Briefly, TOPICS-MDS consists of pooled data from various research projects, which differ across study design, sampling framework, and inclusion criteria. The older persons' data in TOPICS-MDS were collected from the TOPICS-MDS questionnaire for care receivers and combined from validated scales covering various domains of health and well-being [3]. All data were cleaned locally using a standardized protocol. Anonymized individual-level data were then submitted to a central institution (Radboud University Medical Center, Nijmegen, The Netherlands) for further validation checks and creation of the pooled data set.

Because various research projects submitted information to TOPICS-MDS, the database is dynamic in nature and is thus regularly updated with new observations. Our present analysis used the second version of the data set available as of November 2015 and was based on 53 research projects with data available of 39,057 older persons. TOPICS-MDS is a fully anonymized data set available for public access, and therefore this analysis was exempt from ethical review (Radboud University Medical Center Ethical Committee review reference number CMO 2012/120).

Comparative Measures

The original TOPICS-CEP was used as a reference standard. TOPICS-CEP scores range from 0 (worst possible state) to 10 (best possible state). It is based on eight domains: morbidity (17 dichotomous items), functional limitations (15 dichotomous items), emotional well-being (5 items of five-point Likert scale), pain experience (1 item of three-point Likert scale), cognitive problems (1 item of three-point Likert scale), social functioning (1 item of five-point Likert scale), self-perceived health (1 item of five-point Likert scale), and self-perceived quality of life (QOL) in general (1 item of five-point Likert scale). Detailed information about TOPICS-CEP domains and calculation of the summary score can be found elsewhere [4,10].

Other comparative instruments were two QOL measures already included in TOPICS-MDS: a modified Cantril Ladder and the EuroQol five-dimensional questionnaire (EQ-5D) utility index. The modified Cantril Ladder describes a respondent's general QOL on the basis of a self-rated score ranging from 0 (worst state) to 10 (best state) [3,11]. The EQ-5D is a validated measure of HRQOL covering five dimensions (mobility, self-care, daily activities, pain/discomfort, and anxiety/depression) with a weighted utility index ranging from -0.33 to 1.0 [12]. In this study, the weightings were based on the Dutch population [13].

Sample Selection and Analyses

The selection of study samples is described in Figure 1. Participants aged 65 years and older in the data set (further defined as the primary sample) were selected, similar to the minimum age of participants who were included to derive TOPICS-CEP preference weights [4]. Subsequently, participants were further selected for the following analyses.

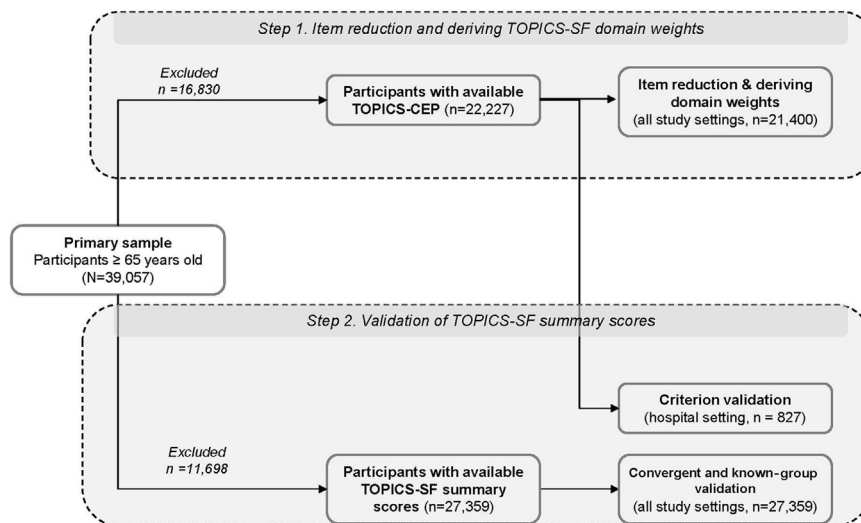


Fig. 1 – Selection of study participants. TOPICS-CEP, The Older Persons and Informal Caregivers Composite End Point; TOPICS-SF, The Older Persons and Informal Caregivers Survey Short Form.

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