LETTER

Cross-cultural adaptation of the German version of the Quality of Life in Alzheimer's Disease scale - Nursing Home version (QoL-AD NH)

Dementia is a chronic and currently incurable syndrome. Therefore, quality of life (QoL) is a major goal when caring for people with dementia (Gibson *et al.*, 2010) and a major outcome in dementia research (Moniz-Cook *et al.*, 2008). The measurement of QoL, especially proxy-rating, is challenging because of the proxy-perspective (Pickard and Knight, 2005), reliability (Dichter *et al.*, 2016), validity (O'Rourke *et al.*, 2015), and responsiveness (Perales *et al.*, 2013). Probably due to these challenges, it has not been possible to show positive effects for QoL in almost all non-pharmacological interventions for people with dementia (Cooper *et al.*, 2012). One recommended (Moniz-Cook *et al.*, 2008) and frequently used instrument is the Quality of Life in Alzheimer's Disease scale (QoL-AD), which was originally developed in the US for community-dwelling people with dementia. The QoL-AD consists of 13 items based on a 4-point Likert scale ranging from "1"=poor to "4"=excellent (Logsdon *et al.*, 1999). The original instrument has been adapted for people living in nursing homes (NH) by Edelmann *et al.* (2005). For the NH version, two items of the original version (Money, Marriage) were removed and four items added (People who work here, Ability to take care of oneself, Ability to live with others, and Ability to make choices in one's life). Both the original version and the NH version allow self-rating of QoL by people with dementia themselves as well as proxy-rating by family members or professional caregivers (Logsdon *et al.*, 1999). Whereas a detailed user manual is available for self-rating, none is available for proxy-rating. Thus, it is unclear whether the items have to be rated from a proxy-proxy or patient-proxy perspective. Based on a proxy-proxy perspective, the caregiver assesses the QoL of a person with dementia from the proxy perspective. This perspective differs more from a QoL self-rating than it does from a patient-proxy perspective. In the latter perspective, a proxy assesses the QoL of a person with dementia just as he/she thinks that the person with dementia would rate him or herself (Pickard and Knight, 2005). Ratings of patients' QoL from a proxy perspective differ more from patients' self-ratings than ratings of a proxy taken from the patient's perspective (Pickard and Knight, 2005).

Since only the Qol-AD 13-item version was available in German, we carried out a cross-cultural adaptation of the QoL-AD NH, applying an established guideline (Beaton *et al.*, 2000) consisting of five steps (translation, synthesis, back-translation, expert committee review, pretesting). During the forward translation process, two persons independently translated items and response options into German. Both translators were native German speakers with excellent English language skills. Both forward translations were synthesized into one preliminary German version after discussion of ambiguities and discrepancies. Two English native speaker translators performed the back-translation. These translators have excellent skills in German and both have been involved with translation issues in research before. Both were blinded to the original English version of the QoL-AD. The two backward translated versions were compared and discrepancies were highlighted. All four translators, one additional dementia researcher, one NH manager experienced in the field of dementia care, and the project coordinator discussed the results. Agreement was achieved for all items except one. For item 2 (Energy) the expert committee was not confident whether only the single word "Energy" or the alternative term "Motivation" could convey the meaning regarding the physical and psychological components of the item.

Therefore, two translations of item 2 (Energy) and one for each of the remaining 14 items were looked at carefully in cognitive interviews with caregivers as proxy-raters (Willis, 2005). The convenience sample consisted of 29 professional caregivers from four NHs who were interviewed individually ($n = 14$) or in three focus groups ($n = 15$). NHs collaborating in previous and recent studies were asked for participation (Köpke *et al.*, 2012; Richter *et al.*, 2015). In all NHs both a focus group interview and individual interviews were conducted. Participants were recruited by NH managers and could choose between participation in focus groups or individual interviews. Before the interview participants were not familiar with the QoL-AD NH. At the beginning of the interview, each caregiver rated (patient-proxy) a person with a formal dementia diagnosis whom he/she knew well. Ratings lasted 3.2 minutes on average (see table S1). Afterwards, each caregiver was asked about his understanding of the QoL-AD NH items based on different cognitive probes (Willis, 2005). The study was approved by the ethic committee of the University of Lübeck (14–239).

In summary, the cognitive interviews yielded the following results: In the German language the word "motivation" represents the meaning of item 2 (Energy) well and no other explanatory word is necessary. In general, respondents had no problems with understanding the items with the exception of item 8 (Self overall). The difference between item 8 and 15 (Life overall) was not clear for some raters. Other raters struggled to understand the item in general. After a short explanation interpreting item 8 in relation to the self-image of the resident, most raters were able to respond. Item 7 (Friends) revealed a higher number of missing values due to a frequent lack of friends.

In conclusion, the German version works well with only one item (Item 8: Self overall) requiring a more detailed description. Both authors of the original QoL-AD and the QoL-AD NH were informed about all steps of the cross-cultural adaptation process and approved the back-translation of the final German QoL-AD NH (self and proxy). The next stage of the cross-cultural adaptation will be an evaluation of the reliability and validity in a large German sample of people with dementia (Richter et al., 2015). Possible differences in reliability and validity of the QoL-AD NH proxy (patient-proxy or proxy-proxy) will be investigated, aiming for a better understanding of the best proxy-perspective regarding the Qol-AD NH.

Conflict of interest

None.

Description of authors' roles

Study Design: MND, EMW, GM, SK, Data Collection and analysis: MND, EMW, First Draft of the Manuscript: MND, Manuscript Preparation: MND, EMW, GM, SK.

Supplementary material

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