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Implementation of Quality of Life Assessment in Long Term Care

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In their systematic review of scales assessing quality of life (QoL) in people living with dementia, Hughes, Farina, Page, Tabet, and Banerjee (2019) did not identify any existing instrument applicable for long term care with sufficient psychometric properties, feasibility and availability.

The most important quality of any instrument is its content validity, which is defined as *'the degree to which the content of an instrument is an adequate reflection of the construct to be measured'* (p 1160; Terwee et al., 2018). As Hughes et al. (2019) concluded, content validity was only formally evaluated in one of the nine instruments reviewed (QUALIDEM; Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007).

The findings of Hughes et al. (2019) raise two central issues of concern. First, implementing QoL-assessments requires certainty that the measurement is tapping what we are interested in. We need to know if the conceptualizations and items in the instrument reflect the important aspects under study from the view of people living with dementia. Next, lack of proper standardized measurement of QoL is a potential source of error in both clinical settings and research reports. Working in evidence-based practice (Melnik, Fineout-Overholt, Stillwell, & Williamson, 2010), this has significant implications for reaching correct conclusions about effective and helpful approaches in any assessment of health interventions.

However, as several recent initiatives have focused on developing clinically relevant core outcome sets for people living with dementia, we are optimistic about implementing systematic QoL assessment in long term care. These initiatives target both issues by recommending standardized assessment packages, as well as ensuring experts living with dementia inform the content validity of these sets of instruments. The COMET initiative ([COMET Initiative | Home \(comet-initiative.org\)](https://comet-initiative.org)) is currently working on and publishing core outcomes important for *home-dwelling* people living with dementia (Harding et al., 2019; Reilly et al., 2020). ICHOM have developed a standard core outcome set for people living with dementia throughout the disease process ([Dementia – ICHOM Connect](https://www.ichomconnect.org))

While Hughes et al. (2019) used a systematic approach from the Consensus based Standards for selection of health Measurement Instruments (COSMIN) initiative, more refined and comprehensive COSMIN-ratings for reviewing patient rated outcome instrument (PROMS)

have been published recently (L. B. Mokkink et al., 2017; Prinsen et al., 2018; Terwee et al., 2018). In particular, Terwee et al. (2018) describes a systematic evaluation of content validity, allowing reviewers to evaluate the content validity based on available knowledge about the instruments. We strongly advice researchers and practitioners to attempt this systematic approach, to gain information about the appropriateness of instruments.

For PROMS, securing content validity includes the relevance, comprehensiveness, and comprehensibility of the instrument, as evaluated by members of the *target group*. If evidence of content validity is absent, investigating this by conducting one's own qualitative interviews or focus groups (Brod, Tesler, & Christensen, 2009) is a better option than developing a new instrument. As Santana-Berlanga, Porcel-Gálvez, Botello-Hermosa, and Barrientos-Trigo (2020) identified 24 instruments assessing quality of life applicable for persons with dementia living as “institutionalized older adults”, adding new QoL-instruments to this pool will increase the problem of a lack of systematic measurement and make comparisons in meta-analyses complicated. Investigating the content validity of existing PROMS where people living with dementia are included as experts, is not only the gold standard (Terwee et al., 2018), but is also something we believe people living with dementia want to contribute to. Participating in research may well provide side-effects of feeling useful, empowered, and valued (Øksnebjerg et al., 2018).

One part of content validity is ‘relevance’, and here a central criteria is an appropriate recall period (Terwee et al., 2018). In general, recall bias is a problem for all aggregated retrospect ratings evaluating longer time-intervals (Shiffman, Stone, & Hufford, 2008). For residents in care homes living with moderate to severe dementia, their current emotional state may interfere with the scoring of their past experiences (Kolanowski, Hoffman, & Hofer, 2007). Thus, a proper recall period is critical to ensure valid QoL-ratings, and several inquiries advocate for *momentary* assessment to increase validity and decrease the recall bias of self-reports (Clarke et al., 2020; Shiffman et al., 2008; Øksnebjerg et al., 2018). For implementing QoL-assessments in long term care, applying a momentary focus, or conducting assessment through interviews, will probably facilitate self-report for people living with dementia longer throughout the time of illness (Ferring & Boll, 2010; Logsdon, Gibbons, McCurry, & Teri, 2002). Meta-analyses suggest dementia severity is not correlated strongly with self-reported quality of life (Martyr et

al., 2018), and implementation of momentary assessments would help clinicians detect drift from individual baselines and intervene when needed.

The feasibility assessment by Hughes et al. (2019) is valuable for practitioners and researchers seeking to use any of the reviewed instruments. In the conclusion, it is stated that the instruments “function poorly” based on their psychometric properties. But do they function poorly, or are they just not investigated thoroughly enough? COSMIN (L. Mokkink et al., 2010; L. B. Mokkink et al., 2017) offers a strict assessment of instruments. In our experience, many instruments will easily get a minimal score as the “lowest score counts”.

As opposed to Hughes et al. (2019), we strongly discourage using dementia-specific instruments for the whole population in long term care to compare aggregated scores or individual development. The content validity of dementia-specific instruments is developed to capture specific issues for this condition and using a dementia-specific instrument for all care home residents would in our view suggest dementia is inevitable for this multifaceted population. We fear implementation of dementia-specific scales in general would lead to implicit attitudes of expecting cognitive impairment in people in care homes living there for other reasons. If the aim is to compare individual scores or aggregated scores over time, using generic instruments for all residents may be a better option.

Content validity is always context-specific (Terwee et al., 2018), and instruments with low content validity in one context may have high content validity in other contexts. Nevertheless, the most important assessment is to evaluate what one wants to measure and find the best instrument fit for this purpose. Other instruments have been recommended for this population based on their total evidence and feasibility, including assessment from the view of people living with dementia. ICHOM recommends Quality of Life-AD (Logsdon, Gibbons, M., & Teri, 1999) and Quality of Wellbeing Scale-Self-administered (Sieber, Groessl, David, Ganiats, & Kaplan, 2008) to assess overall QoL and well-being. These are freely available for non-profit use when registering on the ICHOM-website. Another interesting approach is to look at, or even develop, item-banks based on item response theory (Edelen & Reeve, 2007), where generic questions are applicable for a variety of populations (see for example [PROMIS \(healthmeasures.net\)](https://www.healthmeasures.net)). These item banks are created to ensure optimal scalability of the unidimensional items, where each item corresponds to a level of quality of life. In practice, the

item-bank is adjusting to the resident and terminates the questionnaire when the QoL-level is detected. We hope establishing content validity in the most promising instruments is a target for future research and we encourage feasible and available instruments to be refined.

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