

WHICH MEASURES ASSESSING QUALITY OF DEATH AND DYING AND SATISFACTION WITH CARE AT THE VERY END OF LIFE HAVE BEEN PSYCHOMETRICALLY VALIDATED? A SYSTEMATIC REVIEW

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Introduction The very end of life can be associated with pain, anxiety and caregiver burden. Numerous measures seek to assess the quality of death and dying and satisfaction with care, but there is a lack of evidence and consensus on the best tools.

Aims To identify all existing tools for assessing quality of death and dying and the quality of care and satisfaction with care at the very end of life, and systematically evaluate those which have been psychometrically validated.

Method Four databases (Medline, Embase, Cinahl and Psycinfo) were searched in February 2016 using a combination of MeSH and free-text terms on end of life and satisfaction with care. Article titles, abstracts and full-text papers were reviewed to identify all papers reporting multi-item measures for assessing quality of death and dying and/or quality of care and satisfaction with care at the very end of life. Articles reporting on at least one psychometric investigation of the measures identified were then assessed for quality, using the COSMIN checklist (Mokkink, 2010).

Results The initial search terms identified 4136 articles after excluding any duplicates. Seventy-seven papers, reporting 48 different measures, met the initial inclusion criteria. The most commonly used measures were the Quality Of Death and Dying (QODD; Patrick, 2001) and FAMCARE (Kristjanson, 1986). Both have been validated in a variety of cultural settings and participant groups.

Conclusion Many measures assess quality of death and dying and satisfaction with care, but few have been thoroughly validated. QODD and FAMCARE are the best of those assessed.

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