Measuring Health Related Quality of Life in Persons with Dementia

Abstract:

Background: Dementia affects many aspects of the quality of the lives of people with dementia, particularly their ability to function socially and to live independently. Measuring health related quality of life (HRQOL) in this area poses unique challenges. This paper briefly outlines these challenges and describes instruments considered to be the most useful and appropriate.

Methods: A literature search of CINAHL, EMBASE, MEDLINE and PSYCINFO was conducted to identify papers reporting the development, testing or application of instruments measuring HRQOL in persons with dementia. Review criteria were: availability; cost and ease of administration; suitability across disease stage; psychometric properties; and the availability of clinical and comparison data.

Results: Six instruments were considered to be the most useful and appropriate: Quality of Life in Alzheimer’s Disease (QOLAD), DEMQOL, Quality of Life in Late-Stage dementia (QUALID), Dementia Quality of Life instrument (DQOL), Cornell Brown Scale for Quality of Life in Dementia (CBS), and the Alzheimer Disease-Related Quality of Life (ADRQOL). All are readily available, short and easy to administer. Psychometric properties are good and clinical data is available. QOLAD and DEMQOL are the most sensitive to disease stage and both have patient and proxy versions. QUALID is the only instrument specifically suited to late stage dementia.

Conclusion: Measuring HRQOL in dementia poses difficulties relating to disease stage, self report vs. proxy measures, and subjective vs. objective measures. Several instruments have been found to be appropriate; however QOLAD and DEMQOL are the most suitable for use across a range of disease stages and have the advantage of having both patient and proxy versions available. QUALID is well suited for the nursing home setting.