# Two-Year Course of Quality of Life in Nursing Home Residents with Dementia

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**Objective:** *To assess the course of quality of life (QoL) in nursing home residents with dementia and to study its predictors.* **Methods:** *This longitudinal, multicenter, observational cohort study with a 2-year follow-up looked at 290 residents with dementia, who lived in 14 dementia special care units in nine nursing homes in the Netherlands. QoL was assessed with the Qualidem, providing a total score and QoL profile with nine subscales. Residents were assessed at five assessments: every 6 months during 2 years. A linear mixed model was used for data analysis.* **Results:** *No change was found in the Qualidem total score (range: 0–111) over 2 years. However, a significant increase of QoL over time was seen in the subscales "Care relationship," "Negative affect," "Restless tense behavior," "Positive self-image," "Social isolation," and "Feeling at home." A significant decrease of QoL was seen in the subscales "Positive affect," "Social relations," and "Having something to do." Most predictors of the course of QoL were found for the subscales "Positive self-image" (sex, Global Deterioration Scale, Severe Impairment Battery, Activities of Daily Living, and Neuropsychiatric Inventory) and "Having something to do" (Global Deterioration Scale, Severe Impairment Battery, and Activities of Daily Living). Sex and Neuropsychiatric Inventory at baseline were the predictors found most frequently.* **Conclusion:** *The total QoL score was stable over a 2-year period. However, QoL subscales showed multidirectional changes. The largest QoL decline in the subscale "Having something to do" suggests that more attention should be given to useful activities in nursing home care.* (Am J Geriatr Psychiatry 2018; ■■:■■–■■)

**Key Words:** Quality of life, dementia, nursing home, long-term care, longitudinal

**Highlights**
- A 2-year longitudinal, multicenter, observational cohort study on the course of quality of life (QoL) of nursing home residents with dementia, measured with Qualidem.
- The total Qualidem score was stable over 2 years.

- The underlying Qualidem subscales showed a significant increase of QoL in six subscales and a significant decrease of QoL in three subscales.
- The largest decline of QoL was found in the Qualidem subscale "Having something to do."

## INTRODUCTION

Improving or preserving quality of life (QoL) is one of the most important goals in the care for persons with dementia. Especially in nursing home residents, who often have a wide array of somatic and neuropsychiatric comorbidity, focus of care should not only be directed at the absence of disabling symptoms such as pain or the maintenance of cognitive functions but also at the broader concept of QoL.[1,2] The lack of curative treatment options and the progressive and severe nature of dementia further emphasize the need to find ways to positively influence QoL. This is recognized by studies that focus on the effect of pharmacologic and psychosocial interventions on QoL,[3–5] making QoL an important outcome in dementia research.

QoL has been conceptualized in many ways. In healthcare QoL is commonly approached from a well-being perspective.[6] As such, it is considered to be composed of multiple dimensions and to regard subjective (affective and cognitive) evaluation of these dimensions. In these approaches psychological well-being is often considered the ultimate outcome.[7] The narrower concept of health-related QoL focuses on those QoL aspects that are specifically relevant for, or impacted by, a health condition (e.g., dementia). Based on the hypothesis that QoL is different for persons with dementia in the assessment of their QoL, most measurement instruments used cover several dementia-specific QoL dimensions.[8] Importantly, considerable variation exists in the selected QoL domains used in QoL instruments.[5] A further challenge in QoL measurement refers to health-related QoL ideally reported by the individual in question, given the importance of an individual's subjective experience. People with dementia may, however, lose the ability to respond to self-report measures, implying that proxy report or observation instruments need to be used.[9]

To explore the effect of interventions aimed at improving QoL in nursing home residents with dementia, it is necessary to study the course of QoL. Longitudinal studies on QoL in this population are scarce and difficult to compare with one another because of differences in methodology, such as measurement scales and raters.[10–14] The overall QoL in these studies showed no change[10,11] or a (small) decline in QoL over time.[12–14] However, shifts in QoL were seen regarding specific QoL domains in studies that used a QoL profile. For example, the QoL domains negative affect and sadness improved in the study by Oudman and Veurink[11] but declined in the study by Mjorud et al.[12] A similar finding was seen on social interaction and relations: Oudman and Veurink[11] reported an improvement and Lyketsos et al.[13] a decline.

The search for changes in QoL over time in specific QoL domains can be complemented by looking at possible predictors that influence the course of QoL. So far, only baseline QoL is consistently found as a predictor.[10,12–14] Altogether, there is a need for a longitudinal study in nursing home residents with dementia that assesses the course of QoL with an assessment scale providing a QoL profile that is specifically developed and valid for nursing home residents with dementia. Our study aims were to investigate the course of QoL over a 1- and 2-year period in nursing home residents with dementia and to do a first exploration to identify predictors of the course of QoL.

## METHODS

We performed analysis on data from a longitudinal, multicenter, observational cohort study in which residents with dementia living in 14 dementia special care units in nine nursing homes in the Netherlands participated. The nine nursing homes participated in an academic network of nursing homes.[15,16] They were part of public organizations, in which most nursing home residents in the Netherlands live. The nursing homes that participated met the nursing home definition provided by Sanford et al.,[17] who defined nursing homes as a facility that provides 24-hour support and care for persons who need assistance with activities