

# Quality of life in older people with dementia: using nursing staff and family members as proxies

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## Research article

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# Abstract

**Background** To assess health-related quality of life (QoL) of nursing home residents with dementia using the nursing staff and the residents' family members as proxy raters, to determine the level of agreement between both groups, and to analyze how functional independence, the number of challenging behaviors, nursing home suitability, and the rater group influence QoL assessments.

**Methods** Nursing staff and family members assessed residents' QoL using the short version of the Quality of Life in Dementia (QUALIDEM) instrument. The nursing staff also assessed functional independence and the number of challenging behaviors, while nursing home suitability was assessed by the nursing staff and family members. Multiple linear regressions were run with each QoL dimension as the dependent variable.

**Results** The agreement between nursing staff and family members on the QoL dimensions, for n=53 residents with dementia, was relatively poor, and for each QoL dimension, the reported scores were higher among the nursing staff. Residents' functional independence and the nursing home suitability were associated with a higher QoL, and more challenging behaviors were associated with a lower QoL, particularly according to the assessments of the nursing staff.

**Conclusion** Including family members as an additional rater group is recommended as a valuable way to discuss and possibly improve quality of care and QoL. **Keywords:** nursing homes, health-related quality of life, proxy ratings

## Background

Dementia is an illness with steadily increasing prevalence and it strongly affects health care provision. Currently, there are around 1.7 million people living with dementia in Germany alone. In 2060, this number is expected to increase to 2.9-3.3 million depending on the underlying assumptions [1]. People with dementia are often cared for in nursing homes, where the prevalence of dementia among the residents is about 70%, with more than half of those affected are diagnosed with a severe form of the disease [2]. In Hamburg, 16,000 people live in nursing homes facilities and that number is expected to rise in the future. Knowing this background, there is a growing need to maintain or, if possible, even improve the quality of life (QoL) of these residents by offering the highest level of medical, nursing, and social care possible. Additionally, the QoL of people with dementia is regarded as a key outcome both in research and in clinical practice [3,4] and could be a valuable indicator for improving and evaluating nursing care and overall nursing home quality.

Ideally, QoL should be self-assessed, as perceptions of important aspects of a person's life can be highly subjective [5,6]. However, this presupposes that the person is able to understand the construct of QoL and provide reliable answers when performing QoL measurements [7,8].

### Proxy-ratings for residents' quality of life

When individuals are no longer able to report on their own QoL, due to cognitive impairment, family and professional ratings are used as proxies. Proxy ratings, however, often differ from patients' self-reports and from each other depending on the setting and study population [9,10] and studies comparing self-assessed QoL and proxy-rated QoL often showed that individuals rated their QoL higher than proxy raters [11-12].

When the self-assessment of QoL is no longer reliable, it is necessary to compare ratings of different proxy groups, such as nursing staff and family members, to analyze how and why their assessments might differ from each other. Castro-Monteiro et al. [13] used family members (or friends) and the nursing staff to assess nursing home residents' QoL and found that professional caretakers rated residents' QoL higher when they used the generic EuroQol-5D (EQ-5D). This result, however, did not hold true when the disease-specific quality of life in Alzheimer's disease (QoL-AD) scale was applied. Makai et al. [14] also compared nursing professionals' and family members' assessments of residents' QoL and did not find significant differences when a generic QoL measure was used. Furthermore, Clare et al. [15] compared care staff and family members as proxies and found slightly higher ratings when QoL was rated by the care staff with the Quality of Life in Late-Stage Dementia (QUALID) scale. However, the results were not significant. An insignificantly higher care staff assessment was also found by Crespo et al. [3] when an adaptation of the QoL-AD was used. Recently, Roberson et al. [8] found that median nursing staff scores were higher than family's when applying the DEMQOL-Proxy, which is another outcome measure for QoL in Dementia.

These examples reveal the heterogeneity of studies using proxy ratings and demonstrate that results vary depending on the rater groups and the QoL instrument. However, investigating different perspectives of residents' QoL and gathering information from multiple sources remains relevant in obtaining a comprehensive understanding of residents' well-being [16,17].

## **Factors influencing quality of life**

Prior studies have also analyzed whether QoL relates to functional independence, challenging behaviors (such as apathy, aggression, and delusions), and characteristics of nursing homes (such as the suitability of the physical environment and staffing characteristics). Residents with higher functional independence tend to be associated with a significantly higher QoL [18–20], while challenging behaviors were significantly and negatively correlated with QoL [7,10,13,21–22]. In investigations of the role of nursing home suitability and staffing characteristics, the results are less consistent. Nursing home characteristics were often found to have no significant influence on residents' QoL [23–25]. For instance, Samus et al. [25] found no significant effect of a homelike environment on QoL, and Palm et al. [26] did not find a significant difference between type of care units and residents' QoL. Reimer et al. [27] and Abrahamson et al. [28] found a significantly higher QoL for residents in purpose-built special care facilities, than for residents living in traditional institutional settings. Regarding staffing, Degenholtz et al. [29] found no significant relationship between the quantity of nursing staff and QoL, while other studies found that residents' QoL was higher in facilities that were adequately staffed with nursing assistants and activity

staff [28,29]. However, Abrahamson et al. [28] used a composite measure for QoL. Zimmermann et al. [30] applied different measures, namely, the proxy version of the Quality of Life in Alzheimer's Disease Activity measure (QOL in AD-Activity), the QOL-AD, the positive and negative affect portions of the QOL in AD, and the Alzheimer Disease-Related Quality of Life (ADRQL). However, they also used aggregated scores or only distinguished between two dimensions. To the best of our knowledge, there is no study that compares the extent to which various rater groups (particularly nursing staff and family members) differ in how strongly their QoL ratings are related to these predictor variables.

## **Study objectives**

Hence, the objectives of this study are as follows: To compare the QoL ratings for nursing home residents with dementia across two rater groups, namely, nursing staff and family members; and to analyze the role of functional independence, challenging behaviors, and perceptions of nursing home suitability on the QoL assessments of both groups.

## **Methods**

### **Data and research setting**

All nursing homes located in Hamburg, Germany were informed about this study by e-mail and could express their interest in participating in an evaluation performed by nursing staff and family members. Ultimately, between 2016 and 2017, data was gathered from twelve nursing homes that voluntarily participated in this study, using two questionnaires administered to the nursing staff and the family members of residents with dementia. Nursing staff caring for residents with dementia and acting as a reference caregiver completed Questionnaire A about residents' QoL, functional independence, challenging behaviors, and nursing home suitability. The residents' family members answered questionnaire B, which also included residents' QoL and nursing home suitability. The residents' legal representatives provided written consent that the residents' QoL, functional independence, and challenging behaviors could be assessed. The nursing home staff councils gave their approval for the implementation of the employee questionnaire. The authors confirm that this specific study was reviewed and approved by the University of Hamburg's ethics committee before the study began. For this purpose, a declaration of compliance with terms of use and ethical standards from the University of Hamburg's WiSo Laboratory was signed by the authors and the Dean of Research of the Faculty of Business, Economics and Social Sciences. Participation in this study was strictly voluntary, and no remuneration was offered. A unique and untraceable code was assigned to each resident to allow for anonymous matching of responses in the two rater groups. Furthermore, it was ensured that the research for this study caused no harm to the participants.

Within the participating nursing homes, all residents with dementia were eligible for an assessment of their QoL. Of the 531 questionnaires distributed to the staff, 252 were completed and available for analysis, which corresponds to a response rate of 47%. In parallel, 102 questionnaires were completed by the corresponding family members, which corresponds to a response rate of 19%.

For n=53 residents of the sample, both nursing staff and residents' family members completed the questionnaire. All data analyses that aim to compare the ratings of the two rater groups are based on this subsample of n=53 residents.

## **Measures**

We used instruments that were most suitable for our study setting and applied versions that were validated for the use in German language Nursing home characteristics and staffing levels were combined under nursing home suitability. Factor analysis showed that five items loaded on one factor and so they were aggregated into a combined score (see Appendix A for a description of the variables, items, and literature). Items on all scales specifically target residents' observable behaviors (with the exception of nursing home suitability).

### *Dependent variables*

To account for the multidimensionality of QoL, the Quality of Life in Dementia instrument (QUALIDEM) distinguishes between nine dimensions, six of which are also applicable to people with severe dementia. As the large majority of our sample lives with a severe form of dementia, we focus on the behaviors and dimensions which also apply to them. Nursing staff and family members were both asked to rate how often they observed specific behaviors of residents over the last two weeks, with the response categories being never, rarely, sometimes, and frequently. Their answers were then used to calculate a score for each dimension, ranging between 0 and 3. Items were partially recoded so that a higher score always indicates a higher QoL in each dimension. For example, a higher score for the dimension negative affect means fewer negative behaviors and thus a higher QoL, and a higher score for the dimension restless tense behavior means less restless movements, less tense body language, and thus a higher QoL.

### *Independent variables*

To measure functional independence, the nursing staff rated on a 5-point ordinal scale the residents' physical self-maintenance with regard to toileting, feeding, dressing, grooming, physical ambulation, and bathing. On this basis, a combined score was transferred into a percentage rate ranging from 0 to 100.

Further, we used the ten-item version of the neuropsychiatric inventory (NPI), developed for institutional settings (nursing home version), to measure the number of challenging behaviors exhibited by residents, based on prevalence.

Finally, we measured nursing home suitability with five items targeting spatial structure and staffing levels. Nursing staff and family members were asked to specify their agreement with five statements on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

We also generated a dummy variable called 'rater group', for which 0 indicated that the QoL assessment was made by a family member and 1 indicated that the QoL assessment was made by a member of the nursing staff.

Additionally, age and sex of the residents were used as control variables.

## **Analysis procedures**

First, we conducted paired sample t-tests for dependent samples to compare the means for each QoL dimension, depending on the rater groups (nursing staff and family members), for n=53 residents. Second, we calculated the response agreement, the proportion agreement between nursing staff members' and family members' assessments of those residents' QoL and the intraclass correlation coefficients (ICCs) for each QoL dimension. Third, we conducted multiple linear regressions for the six QoL dimensions and the overall QoL score as dependent variables, respectively; functional independence, number of challenging behaviors, and nursing home suitability as independent variables; and age and sex as control variables. Additionally, a dummy variable for the rater group was used to analyze the effect of being either a family member or part of the nursing staff. We clustered standard errors at the resident level. Fourth, we repeated the multiple linear regressions described above for family members and nursing staff ratings separately.

To confirm the robustness of our regression results, we also included severity of the disease as an additional control variable. Furthermore, we conducted a sensitivity analysis using a random effects model. Finally, we repeated the multiple linear regressions for a sample of n=252 residents with dementia, for whom nursing staff members had completed a QoL assessment. All analyses were performed using STATA version 14 (StataCorp LP, College Station, Texas).

## **Results**

### **Descriptive resident characteristics**

Table 1 provides the descriptive statistics for all residents with dementia whose QoL was assessed by family members and the nursing staff. In the sample of n=53 residents, on average, 2.9 challenging behaviors were reported, with agitation and irritability being the most common. It is noteworthy that family members rated nursing home suitability as lower than the nursing staff did.

### **Proxy-ratings for residents' quality of life**

The nursing staff rated the dimensions of positive affect and negative affect as the highest, while the family members reported the highest QoL scores for care relationship and positive self-image. The lowest ratings for both groups were found for restless tense behavior. By comparing the means, we found a higher nursing staff assessment for all six QoL dimensions (see Table 2). The largest deviations were found for negative affect and the smallest deviation for care relationship. For four dimensions, the deviations were also statistically significant.

As a next step, we examined the agreement between the nursing staff and family members. The proportion of the exact response agreement for the 18 items ranged from 20% ("The resident is capable of enjoying things in daily life") to 56% ("The resident responds positively when approached"). On the

dimension level, the results reveal a proportion agreement of 25% for restless tense behavior to 47% for care relationship. The ICCs ranged from 0.21 for restless tense behavior to 0.70 for the care relationship. The ICCs also indicated moderate to good agreement for the dimensions care relationship, positive affect, and social isolation (see Table 2).

### **Factors influencing quality of life**

We analyzed how different factors, including the rater group (measured by a dummy variable with 0 for family member and 1 for nursing staff), influenced the assessments of residents' QoL (see Table 3, 1<sup>st</sup> column for each dependent variable). The results confirmed that the nursing staff rated residents' QoL as higher than the family members did. A higher score for each QoL dimension indicates a better QoL and therefore for the negatively worded dimensions less negative effects, less restless tense behavior and less social isolation. The coefficients for the rater group were significantly positive for the QoL dimensions positive affect ( $\beta=0.438$ ), social relations ( $\beta=0.302$ ), and social isolation ( $\beta=0.356$ ), which is largely consistent with the results of the paired-sample t-tests. The only inconsistency concerned residents' negative affect, for which the coefficient for the rater group was positive but insignificant ( $\beta=0.291$ ).

For functional independence, we largely found a positive effect on QoL, suggesting that higher functional independence significantly increases social relations ( $\beta=0.009$ ), while significantly reducing restless tense behavior ( $\beta=0.014$ ). More challenging behaviors were associated with lower QoL. In particular, we found that challenging behaviors are significantly associated with more social isolation ( $\beta=-0.071$ ). Finally, for nursing home suitability, most of the coefficients were positive, yet none of them was significant.

### **Factors influencing quality of life depending on the proxy rater group**

Finally, we carried out separate analyses to identify how the influence of factors on QoL ratings may differ depending on the rater group for each QoL dimension (Table 3, 2<sup>nd</sup> and 3<sup>rd</sup> column for each dependent variable).

We found that functional independence played a significant role in the nursing staff assessments for the QoL dimensions positive affect ( $\beta=0.014$ ) and social relations ( $\beta=0.009$ ). In contrast, only one significant association between functional independence and QoL was found for the family members' ratings, namely on restless tense behavior ( $\beta=0.017$ ).

The number of challenging behaviors also played a significant role in the nursing staff assessment of four QoL dimensions. The effect on social isolation in the combined regressions remained significant when only the nursing staff ratings were analyzed ( $\beta=-0.133$ ). Additionally, the negative effects of challenging behaviors on the care relationship ( $\beta=-0.083$ ), negative affect ( $\beta=-0.065$ ), and restless tense behaviors ( $\beta=-0.137$ ) became significant. Focusing on the family member assessments only, none of the significant findings held.

Within the separate analyses, we found a positive and significant effect of nursing home suitability only

on social isolation in the assessments made by the nursing staff ( $\beta=0.244$ ), while no significant effects were found in the combined analysis or the separate family member assessments.

### **Results of the sensitivity analyses**

Including severity of the disease as an additional control variable and estimating a random effects model did not alter the results of the main analysis. The significant effects found in the subsample of residents with dementia were confirmed after repeated analyses on all residents with dementia assessed by the nursing staff ( $n=252$ ). Furthermore, results suggest that higher functional independence might significantly increase care relationship and decrease restless tense behavior, while nursing home suitability was positively associated with positive affect, negative affect, and care relationship (see Appendix B for descriptive resident characteristics and Appendix C for regression results).

## **Discussion**

Our findings showed a general tendency for the nursing staff to rate the QoL of residents with dementia as higher than their associated family members do. However, significant differences do not exist across all QoL dimensions. There is variation not only in the average ratings between the two rater groups but also in the extent of agreement between them. For some dimensions, the share of identical ratings and the ICCs are substantially higher than for others. Finally, differences in the average ratings and the agreement, as indicated by the ICCs, seem related, but also show some variation across the QoL dimensions.

For care relationship, we found no significant deviation in means, a strong proportion agreement and a good agreement when we calculated the ICCs, and no significant difference between family member and nursing staff agreement in the combined regression analyses. From this we conclude that the greatest agreement between the nursing staff and family members exists in the assessment of care relationship. For all other dimensions, we found different combinations of significant deviations in means, low proportion agreement, poor to moderate agreement when we calculated the ICCs, and a significant difference between the two groups in the regression analyses. Obviously, the level of QoL assessments depends on whether they were made by the nursing staff or by the family members.

### **Proxy-ratings for residents' quality of life**

Our results show that the assessment of resident's QoL tends to be higher when performed by the nursing staff. Higher nursing staff assessments, compared to family members' assessments, are in line with the findings of other studies [3,13,15,38]. However, Castro-Monteiro et al. [13] and Clare et al. [15] used an aggregated score for QoL and therefore did not differentiate between QoL dimensions. Crespo et al. [3] used the QOL-AD and assessed differences in ratings on the item level. For the 15 items, they found significantly higher scores given by the staff for six items ("physical health", "energy", "mood", "memory", "family", "ability to take care of himself/herself") and a significantly higher score by the family members in one case ("ability to do things for fun"). As these items cover distinct topics compared to the items

comprising the QUALIDEM dimensions, the results are hardly comparable, and our study provides some additional insights. One potential explanation for the higher nursing staff ratings relies on different perspectives and expectations between the two rater groups. The nursing staff might answer questions regarding QoL while focusing on residents with a more progressive dementia disease, while family members may assess the residents' current QoL in relation to a former status when psycho-geriatric services had not been necessary [13,14]. Additionally, the residents' observable behavior may differ when they are being visited by a family member than when they have everyday interactions with the nursing staff.

### **Factors influencing quality of life**

Regarding predictors of QoL, we found that functional independence and fewer challenging behaviors and nursing home suitability were associated with higher QoL among residents; this finding is also consistent with those of prior studies. Functional independence is usually associated with higher QoL or related factors, such as well-being [39,40], while challenging behaviors, such as depression, anxiety, and agitation, are associated with lower QoL [7,21–22,25]. Our study shows that the results of prior research also hold true in the context of German nursing homes, and additionally, addresses how functional independence, challenging behaviors, and the nursing home suitability are related to the various QoL dimensions depending on the dimensions and the rater group.

Our results also show that for the QoL assessment the relevance of functional independence, challenging behavior, and nursing home suitability differs vastly between the two rater groups. The nursing staff attached great importance to residents' functional independence and the number of challenging behaviors and some importance to the nursing home suitability. In contrast, family members' QoL assessments seemed to be mostly independent of residents' functional independence, the number of challenging behaviors, and the nursing home suitability. For them only one QoL dimension, namely less tense behavior, was associated with one predictor variable: functional independence.

Overall, functional independence was most frequently found to have a significant effect on residents' QoL and should be promoted due to its positive effect. Enabling residents to participate in nursing home activities and helping them to maintain contact with other residents, nursing staff, and visitors might have resulted in a higher QoL score for social relations. Additionally, functional independence was associated with a more frequent display of positive affect. Residents might feel more comfortable, and therefore display more signs of being content and cheerful, when they are able to regulate their toileting and bathing themselves.

Challenging behaviors were significantly negatively associated with care relationship, negative affect, restless tense behavior, and social isolation. In particular, agitation and irritability can complicate the care relationship between residents and nursing staff, while aberrant motor behavior, as a component of challenging behaviors, can lead to more restless tense behavior. At the same time aberrant behavior can lead to social isolation by means of residents rejecting contact with others, or being rejected.

For both factors, functional independence and challenging behaviors, the question might be whether they are actually linked to residents' QoL, or whether both are used as a 'proxy' in the assessment of QoL, so that raters simply assume that residents with lower functional abilities and more challenging behaviors must have a lower QoL. While it is possible that raters' assessments are influenced by those factors, we also believe that the QUALIDEM's response scale (how often raters observed specific behaviors of residents over the last two weeks, such as smiling or calling out) offers the objectivity needed to rate QoL independently.

In the literature, the influence of nursing home characteristics, such as the spatial and process suitability of the nursing home and sufficient staffing levels, has not yet been conclusively clarified. It is to be expected that nursing homes focusing on the care of residents with dementia will be able to adapt their care processes, premises, and their resident and staff composition and thus offer a better working and living environment, which in turn can benefit the QoL of the residents. In addition, nursing staff who is specialized in caring for residents with dementia may be more experienced and more confident in working with this group of residents. To add to the literature, we included nursing home suitability as a third predictor and found a significant positive association on social isolation, but only in the nursing staff assessments. However, the instrument used in this study combining nursing home characteristics and staffing levels cannot be directly compared to instruments used in prior research.

### **Practical implications**

Our results indicate that promoting functional independence, reducing the prevalence of challenging behaviors, and a better nursing home suitability is associated with higher QoL for nursing home residents. Nursing homes should therefore promote measures that help residents maintain or regain functional independence and also create an environment that supports an adequate approach to deal with or reduce challenging behaviors. The systematic measurement of functional independence and challenging behavior with validated instruments might be a good starting point to identify residents who display challenging behaviors and whose functional independence might be improved by training and therapy.

At the same time, QoL assessments are a useful way to identify areas where quality of care and QoL in the long-run can be improved. Low scores for the care relationship, for example, can hint at ongoing conflicts between the nursing staff and residents, while low scores for social isolation can reveal that attempts should be made to promote interactions between residents. In addition, a cooperation between nursing homes and external organizational units, e.g. church groups or schools, could be beneficial to combat social isolation.

An inclusion of the residents' family members may provide an assessment of QoL from a different perspective. While similar assessments between both groups could serve as a validation, deviations might open a discussion about expectations and appropriate measures to reduce them. This approach can result in concrete actions for each resident while accounting for the different perspectives and

individual characteristics of residents in terms of personality, type and severity of illness, and general needs.

A regular assessment of residents' QoL could remind the nursing staff of its multidimensional nature, the manner in which different dimensions should be addressed during the daily care process, and how QoL is changing over time for each resident specifically. However, in order for positive results to unfold, a process of QoL assessments, rounds of discussion, and derivations of recommendations for action must be conducted regularly. Nursing home care is often focused on physical care and food supply due to time pressures and high workloads, leaving less time for the staff to meet the other demands and needs of residents with dementia. Demands and needs such as social and physical contact, affection, and self-determination are independent of the presence of dementia. However, declining communication skills, impaired memory and judgement as well as personality changes of residents with dementia make it difficult for the staff to understand and fulfill those demands and needs. Thus, sufficient training and staffing are needed to respond to those situations and improve overall care.

### **Limitations and future research considerations**

The limitations of our study are consistent with those of other papers in this area. Studies to investigate QoL in residents with dementia are usually cross-sectional and characterized by small sample sizes due to an old and multimorbid population [4,7,12]. When comparing the rater assessments for the same resident, more observations would have been desirable, and longitudinal data could have provided insight into the changes in the QoL of residents and the QoL assessments over time. Another difficulty is that data collection on site is cumbersome, involving nursing staff and family members. Finally, as with similar studies, the generalization of our results is limited by the particular setting of nursing homes and a potential self-selection bias [6-7,13].

## **Conclusion**

The nursing staff and residents' family members applied the QUALIDEM as a health-related QoL instrument to measure the QoL of nursing home residents with dementia. Functional independence, fewer challenging behaviors, and nursing home suitability were confirmed as drivers of higher QoL and were the main influencers of the assessments of the nursing staff. In general, the nursing staff rated residents' QoL higher than the family members did; thus, the agreement between nursing staff and family members was mostly poor to moderate. This study analyzes how different factors influence different QoL dimensions of nursing home residents with dementia and argues for the use of QoL assessments by the nursing staff and residents' family members to potentially improve quality of care and QoL.

## **Abbreviations**

ADRQL            Alzheimer Disease-Related Quality of Life

DEMQOL        Dementia Quality of Life

EQ-5D	EuroQol-5D
ICCs	Intraclass Correlation Coefficients
n.a.	not applicable
NPI	Neuropsychiatric Inventory
PSMS	Physical Self-Maintenance Scale
QoL	Quality of Life
QOL-AD	Quality of Life in Alzheimer's Disease
QOL in AD–Activity	Quality of Life in Alzheimer's Disease Activity
QUALID	Quality of Life in Late-Stage Dementia
QUALIDEM	Quality of Life in Dementia

## Declarations

### *Ethics approval and consent to participate*

This study was submitted to and approved by the University of Hamburg's ethics committee and a declaration of compliance with terms of use and ethical standards from the University of Hamburgs' WiSo Laboratories was obtained. In addition, a written consent to participate in this study was obtained from all participants.

### *Consent for publication*

Not applicable

### *Availability of data and material*

The datasets generated and/or analysed during the current study are not publicly available due lack of consent of sharing raw material, but parts of the material can be available from the corresponding author on reasonable request.

### *Competing interests*

The authors declare that they have no competing interests.

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This study was not supported by any research grant.

## *Authors' contributions*

DS and VW made substantial contributions to the conception and design of the work as well as the acquisition, analysis, and interpretation of data. DS drafted the work and VW and AK substantively revised it. All authors read and approved the final manuscript.

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Not applicable

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## Tables

**Table 1: Resident characteristics**

Variable	Sample (n=53), mean or %
Age	86.1 (7.9) years
Female sex	90%
Severity of the dementia disease	13% mild 35% moderate 52% severe
Functional independence <sup>a</sup>	39.3 (17.8) out of 100
Number of challenging behaviors <sup>b</sup>	2.9 (2.5) out of 10
Nursing home suitability <sup>c</sup>	4.5 out of 5 (rated by the nursing staff) and 3.6 out of 5 (rated by the family members)

Standard deviation in parentheses

<sup>a</sup> Scale ranges from 0 to 100, with 100 indicating complete functional independence

<sup>b</sup> Scale ranges from 0 to 10

<sup>c</sup> Scale ranges from 1 to 5, with 5 indicating the highest possible suitability

**Table 2: Quality of life assessments and agreement by rater group for each subscale of the QUALIDEM for n=53 residents with dementia**

Dimension	# of items	Nursing staff <sup>a</sup>	Family members <sup>a</sup>	Significance <sup>b</sup>	Proportion agreement	ICC <sup>c</sup>
Care relationship	3	1.94	1.93		47%	0.70
Positive affect	4	2.34	1.84	***	32%	0.40
Negative affect	2	2.38	1.97	***	39%	0.33
Restless tense behavior	3	1.65	1.46		25%	0.21
Social relations	3	2.29	1.85	***	41%	0.25
Social isolation	3	2.08	1.75	***	37%	0.51

- <sup>a</sup> Scales range from 0 to 3 for each QoL dimension, with 3 indicating the highest possible QoL
- <sup>b</sup> Paired sample t-test, \*\*\*p<.01
- <sup>c</sup> Intraclass correlation coefficient. ICC < 0.40 indicates poor agreement, 0.40 ≤ ICC < 0.75 indicates moderate to good agreement, and ICC ≥ 0.75 indicates excellent agreement [37]

**Table 3: Factors influencing residents' (n=53) quality of life based on three regressions for each QoL dimension**

	Both	Nursing staff	Family members	Both	Nursing staff	Family members	Both	Nursing staff	Family members
	Care relationship			Positive affect			Negative affect		
Functional independence	0.005	0.004	-0.003	0.009	0.014**	0.008	-0.003	-0.008	-0.001
Number of challenging behaviors	-0.052	-0.083**	-0.033	0.006	0.035	-0.011	-0.024	-0.065*	0.028
Nursing home suitability	0.078	0.071	0.071	-0.006	0.004	-0.045	0.175	-0.106	0.145
Rater group <sup>a</sup>	-0.042	n.a.	n.a.	0.438***	n.a.	n.a.	0.291	n.a.	n.a.
Age	-0.013	-0.031**	0.011	-0.018	-0.031**	-0.003	-0.021**	-0.011	-0.018
Female sex <sup>b</sup>	0.079	0.113	-0.164	-0.041	0.063	0.205	0.467*	-0.159	0.522
	Restless tense behavior			Social relations			Social isolation		
Functional independence	0.014***	0.011	0.017**	0.009**	0.009*	0.009	0.000	-0.002	-0.000
Number of challenging behaviors	-0.053	-0.137***	0.033	0.005	0.052	-0.048	-0.071*	-0.133***	-0.034
Nursing home suitability	0.143	0.229	0.015	0.090	0.046	0.104	0.100	0.244**	0.172
Rater group <sup>a</sup>	-0.085	n.a.	n.a.	0.302*	n.a.	n.a.	0.356**	n.a.	n.a.
Age	-0.004	-0.011	0.007	-0.031***	-0.032**	-0.023	-0.010	-0.005	-0.021
Female sex <sup>b</sup>	0.203	0.758	-0.697	0.241	0.454	-0.327	0.094	-0.131	0.400

n.a. not applicable; we report standardized beta coefficients for the effect of each independent variable on each QoL dimension  
 \*p≤.10, \*\*p<.05, \*\*\*p<.01

<sup>a</sup> dummy variable with 0=family members; 1=nursing staff

<sup>b</sup> dummy variable with 0= male; 1=female

## Additional Files

File name: Appendix A

Title of data: Appendix A: Variable list

Brief description of the data: Appendix A contains a description of the variables, items, and literature used in this study.

File name: Appendix B

Title of data: Appendix B: Resident characteristics for n=252 residents assessed by the nursing staff

Brief description of the data: Appendix B contains resident characteristics for n=252 residents assessed by the nursing staff.

File name: Appendix C

Title of data: Appendix C: Factors influencing residents' quality of life based on a regression for each QoL dimension for n=252 residents assessed by the nursing staff

Brief description of the data: Appendix C contains regression results for n=252 residents assessed by the nursing staff

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix.docx](#)