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How to measure quality of life in shared-housing arrangements? A comparison of dementia-specific instruments

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Abstract

Purpose The appropriateness of existing quality of life (QoL) instruments in small-scale, homelike care facilities for people with dementia is as yet unknown. This study evaluated the psychometric properties of three QoL instruments in German shared-housing arrangements (SHA).

Method A cross-sectional study was conducted in 36 SHA in Berlin to evaluate the acceptability, internal consistency, and validity (construct, convergent, and discriminant) of three QoL instruments: Alzheimer's Disease Related Quality of Life (ADRQL), Quality of Life–Alzheimer's Diseases (QoL-AD), and measuring QUAlity of LIfe in DEMentia (QUALIDEM).

Results A total of 104 residents (mean age 79.0 years, 73 % female) were included. All instruments showed good acceptability, with QUALIDEM the best. Adequate levels of internal consistency for the ADRQL and QoL-AD and most of the QUALIDEM domains were found. Validity of all the instruments measuring QoL was confirmed.

Conclusions Study findings suggest that QUALIDEM is the preferred instrument to evaluate QoL of residents in SHA, especially due to the high acceptability. Further research is needed to develop and improve these existing measurements.

Keywords Quality of life · Instruments · Dementia · Shared-housing arrangements · Small-scale living facilities

Background

A new international approach to providing individualized care to people with dementia is the implementation of small-scale, homelike living facilities. This trend started

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with ‘group living’ in Sweden, and today, it is widespread across the world, e.g., Greenhouse in the USA [1], small-scale living arrangements in The Netherlands [2], and German shared-housing arrangements (SHA) [3, 4]. SHA are a shift from traditional care in physical, social, and organizational environments and are intended to preserve residents’ quality of life (QoL). Meaningful activities are centered on the daily household, emphasizing the principle of normal living and encouraging residents’ autonomy. In German SHA, 6–8 residents with mild-to-severe cognitive impairment share one large apartment in a mostly urban setting. Community health care providers give 24-h care to the residents. These SHA have comparable domains to those of small-scale living arrangements worldwide: family- and homelike structures, the involvement of family members in daily living, connections with the neighborhood, access to health care, and maintenance of self-determination and autonomy, e.g., by involvement of residents in the decision process, what to eat [4]. These small-scale care arrangements are seen as beneficial to residents in terms of QoL [5].

Quality of life

The improvement of QoL is considered a major outcome in these settings, as the disease has no cure [6–8]. A better quality of life is associated with better capacities of daily living and less apathy [20]. Although the lack of a unique understanding of QoL is frequently discussed [9, 10], providing tailor-made, person-centered care to residents with dementia is intended to improve their QoL [11, 12].

Measuring quality of life

To provide evidence-based care for people with dementia in small-scale living facilities, reliable, valid, and widely accepted QoL instruments are essential, preferably dementia-specific instruments [13]. Self-rating scales are seen as the best way to evaluate QoL [14, 15]. But in a population with severe dementia [16, 17] or in longitudinal evaluations [18], proxy ratings (by family members or nurses [19]) are the method of choice.

The evaluation of QoL in residents with dementia is associated with various problems [20], especially because there is no ‘gold standard’ [21, 22] and not generally agreed upon approach to measuring QoL in small-scale living facilities at all [23]. The Scientific Advisory Committee of the Medical Outcomes Trust warns that ‘an instrument that works well […] in one setting […] may not do so when applied […] in another setting […]’ [24].

Quality of life instruments in small-scale living facilities

Appropriate instruments have to reflect the domains on which small-scale living facilities focus. The conceptual matching to identify an appropriate instrument [24, 25] has been described elsewhere [23]. The Alzheimer Disease Related Quality of Life (ADRQL) [26], the Quality of Life–Alzheimer’s Diseases (QoL-AD) [27, 28], and the QUALIDEM (measuring QUAlity of LIfe in DEMentia) [29, 30] are seen as appropriate instruments to evaluate dementia-specific QoL of residents living in SHA [23]. These instruments reflect the majority of the SHA domains [4].

Neither the psychometric properties of these QoL instruments have been evaluated in these settings nor the comparison of the various instruments has been applied to identify any optimal instrument for this population and setting. However, both approaches are highly warranted to add new knowledge concerning the application or improvement of QoL instruments to assess effectiveness of small, homelike care arrangements. The present study is the first, which compares three appropriate dementia-specific QoL instruments in long-term nursing care, specifically SHA. The main aim of the study was to investigate the psychometric properties and acceptability of three QoL instruments for older people with dementia in SHA.

Method

A standardized cross-sectional study was conducted in 36 SHA in Berlin, Germany. The SHA are located in the urban residential area of Berlin. A mean number of 6.1 (1.7) with a minimum of 3 and up to 8 residents are living in these SHA. The number of full-time equivalent staff, who are working there, is on average 6.1 (2.1). The SHA are all founded before 2009.

Design and sample

Included into the study were all residents of participating SHA, who were signing the informed consent form (themselves or their legal representatives). All residents have cognitive decline, although not all had an official diagnosis of dementia since dementia is under-diagnosed in Germany [31]. All study nurses, engaged in data collection and completed instruments, were registered nurses and had at least 2 years experience of working with the cognitively and physically impaired. The nurses received a training session prior to data collection including conducting interviews with people with cognitive impairment. During interviews, the nurses actively monitored the willingness to participate and signs of (non)verbal dissent or distress of participants. They conducted standardized, face-to-face interviews with nurses working in the SHA and residents.

Measures

The primary measures were the ADRQL [26], QoL-AD [27, 28], and QUALIDEM [29, 30].

The ADRQL [26] consists of 47 items concerning observable behavior. Their occurrence can be 'agreed' or 'disagreed.' Each item is weighted differently. A relative global score and five relative subscales ('social interaction'; 'awareness of self'; 'enjoyment of activities'; 'feelings and mood'; 'response to surroundings') scores are calculated. Because a relative QoL score is calculated, imputation for missing values is not required. A higher score indicates a better QoL (theoretical range for all subscales and global score: 0–100).

The proxy-rated QoL-AD [27, 28] includes 13 subscales (one item each). The range per subscale ('physical health'; 'energy'; 'mood'; 'living situation'; 'memory'; 'family'; 'marriage'; 'friends'; 'self as a whole'; 'ability to do chores around the house'; 'ability to do things for fun'; 'money'; 'life as a whole') is from 1 = 'poor' to 4 = 'excellent'. All items were summed to a global score (theoretical range 13–52). An imputation of up to two missing values was possible by the mean individual score. A higher score is associated with a better QoL.

The QUALIDEM [29, 30] is a 37-item instrument for people with mild-to-moderate dementia. Missing values can be imputed by the expectation-maximisation algorithm. For people with severe dementia, the number of items is 18 and six subscales ('care relationship'; 'positive affect'; 'negative affect'; 'restless tense behavior'; 'social relations'; 'social isolation') [32]. For the version used with those with mild/moderate dementia, there are three additional scales ('positive self-image'; 'feeling at home'; 'having something to do'). Behaviors are rated from 0 = 'never' to 3 = 'daily' or vice versa. A higher sum score indicates a better QoL in each subscale and the global QoL [33].

To increase comparability of all instruments, the scores of all subdomains and the global scores were linearly adapted to a scale from 0 to 100.

Additional measurements included cognitive functioning measured with the mini mental state examination (MMSE; theoretical range 0–30) [34]. A higher score indicates better cognitive functioning. The severity of dementia was measured with the Global Deterioration Scale (GDS) (theoretical range from 1 = 'no' to 7 = 'very severe' level of dementia) [35]; the activity of daily living (ADL) was assessed using the Extended Barthel Index (EBI; theoretical range 0–64 with a higher score indicating better ADL functioning) [36] and apathy by the Apathy Evaluation Scale (AES; theoretical range 18–72 with higher scores indicating more apathetic behavior) [37]. Apathy in this context means a lack of motivation.

Statistical analyses

Statistical model assumptions were examined before performance of further analyses. For the QoL instruments, comprehensive performance testing was conducted (acceptability, reliability, and construct, convergent, discriminant validity) [24]. Multiple linear regression analyses were conducted to identify variables which perform as QoL determinants.

Acceptability

Shorter completion time and a higher item completion rate indicate good acceptability [25, 38].

Reliability

A Cronbach's α of more than .70 indicates good reliability. Additionally, an inter-item correlation coefficient of .30 is sufficient [39].

Validity

Confirmatory factor analyses (CFA) were performed with SPSS AMOS 20®. The goodness-of-fit of each model was assessed with chi-square test, Comparative Fit Index (CFI), and Incremental Fit Index (IFI). Additionally, the root-mean-square error of approximation (RMSEA) was included with 90 % confidence intervals (CI). Nonsignificant chi-squares and values close to one were considered as a good model fit for the CFI and IFI. RMSEA values below .08 were considered to reflect acceptable fit to the model and values smaller than .05 as good fit [40]. Because of the small sample size and the rather complex models, item parceling was used to reduce the number of parameters needed to define a construct of the models and to increase the stability of the parameter estimates [41]. A parcel is an observed variable representing the average of items that is used as an indicator of the latent construct. The single items were assigned to the parcels by their content, to ensure each parcel contained items from each facet of the subdomain [42]. Two manifest indicators per latent construct were created.

For convergent (with ADL functioning [22, 33] and apathy [30, 43, 44]) and discriminate (with age and sex [20]) validity estimation, two-sided Pearson's correlation coefficients and a *t* test with each of the global QoL scores were examined. A moderate correlation between the global

QoL means and mean score convergent or discriminant constructs and a nonsignificant *t* test are indicating validity [45]. The multiple regression model was performed for each global QoL score. Independent variables included into the model were as follows: age, sex, apathy, EBI, and severity of dementia (GDS). For all statistical analyses, the level of significance is set to $p < .05$.

Ethical considerations

The Ethics Committee of the German Society of Nursing Sciences approved the study protocol. According to the German law, whenever a person has a legal representative, it is required for that to provide informed consent. Because most residents in SHA usually have a legal representative [46], the employees of the care providers forwarded written information to the legal representatives of the residents with a request to contact us. After 4 weeks, nonresponders received a reminder.

Results

A total of 104 residents (39.8 %) from 36 SHA were included in the study. The most frequent reason for non-inclusion was that the legal representatives did not answer the request for participation, even after repeat requests. Participation was refused in only five cases. Table 1 shows the residents' characteristics.

Table 1 Sample characteristics ($n = 104$)

Age, years (sd)	79.0 (9.5)
Women	73.0 %
Length of stay, months (sd)	32.8 (23.4)
Official diagnosis of dementia	83.6 %
Type of dementia	
Alzheimer's disease	26.9 %
Vascular dementia	6.7 %
Not specified	38.5 %
Other/mixed	11.5 %
Mini mental state examination (sd)#	11.5 (9.6)
Global Deterioration Scale	
≤4	7.7 %
5	1.0 %
6	50.0 %
7	39.4 %
Extended Barthel Index (sd)##	32.9 (17.7)
Apathy Evaluation Scale (sd)###	51.8 (12.1)

sd standard deviation

Theoretical range 0–30; ## Theoretical range 0–64; ### Theoretical range 18–72

Sample description

The mean age (Table 1) of the study population was 79.0 years, but women (80.4 years) were significantly older than men (75.2 years) (*t* test, $p = .014$). About 84 % of all residents had an official diagnosis of dementia; however, for most of the residents, the diagnosis was not specified. Therefore, most residents are with a nondefined type of dementia. All residents demonstrated some level of cognitive decline. Most people (51.1 %) were considered having severe cognitive impairment (MMSE < 9), while one quarter had moderate (MMSE 10–19) and the other quarter had mild (MMSE 20–26) cognitive impairment. One person (1.1 %) had a MMSE score of 27. Those with a diagnosis of dementia had significantly lower MMSE scores compared to those without an official diagnosis (*t* test $p = .003$; mean 10.0 v. 17.6, respectively). The mean EBI score indicates a moderate functional impairment. About one-third of the residents show a severe impairment (EBI < 21), and another one-third show mild-to-no impairment (EBI > 43). Residents show symptoms of a moderate apathy (AES, 51.8).

Acceptability

Adequate use of the full range of potential responses, and response variability, as indicated by standard deviations, for the QoL measures was found for the QoL-AD and QUALIDEM. Only for the ADRQL, some of the dichotomous items ('He/She will stay around other people'; 'He/She can be comforted or reassured by others'; 'He/She does not respond to his/her own name'; 'He/She gets enjoyment from or is calmed by his/her possessions or belongings') revealed limited variability (up to 96.2 % responders chose the same response option).

All ADRQL questionnaires could be included in the analysis. A total of 58 missing values were identified, however. The proportion of missing values was 1.2 % of all 4,888 possible responses (Table 2), which indicates high acceptability of the instrument. The item with the most missing values was 'being aware of place in the family,' with six missing responses. All other items had a maximum of two missing items. The average time taken to administer the questionnaire was 6.8 (±3.0) min.

For the QoL-AD, seven questionnaires had to be excluded because of more than two missing values. The reason was that the staff lacked certain necessary information. On other 36 questionnaires, several missing values were imputed. One missing value was imputed in 12 (12.4 %) of these questionnaires and two missing values in 24 (24.8 %) questionnaires. The total number of missing values was 60, a proportion of 4.8 % of all 1,261 possible responses (Table 2). This indicates sufficient acceptability.

Table 2 Psychometric properties of the ADRQL, QoL-AD, and QUALIDEM

	Acceptability		Reliability		Validity		
	Time to complete the questionnaire (in minutes (sd))	Ratio of missing values	Cronbach′s α	Mean inter-item correlation	Construct	Convergent$^{\#}$ (EBI* / AES*)	Discriminant$^{\#}$ (Age* / sex**)
ADRQL (global score)	6.8 (±3.0)	1.2 %	$\alpha = .870$	.126	RMSEA = .00 [90 % CI .00, .06]; CFI=1.00; IFI = 1.00; χ^2 (25) = 20.31, $p = .35$	$r = .592$, $p < .001$ / $r = -.654$, $p < .001$	$r = -.096$, $p = .334$ / n.s.
Social interaction			$\alpha = .719$	.175			
Awareness of self			$\alpha = .542$	.141			
Feelings and mood			$\alpha = .770$	.177			
Enjoyment of activity			$\alpha = .442$	.144			
Response to surrounding			$\alpha = .450$	.124			
QoL-AD	3.0 (±2.1)	4.8 %	$\alpha = .739$	.193	Saturated model	$r = .480$, $p < .001$ / $r = -.698$, $p < .001$	$r = .141$, $p = .168$ / n.s.
QUALIDEM (mild-to-moderate)	6.2 (±3.9)	0.2 %	$\alpha = .875$	.178	RMSEA = .07 [90 % CI .03, .10]; CFI = .90; IFI = .91; χ^2 (99) = 134.33, $p = .01$	$r = .480$, $p < .001$ / $r = -.698$, $p < .001$	$r = -.067$, $p = .603$ / n.s.
Care relationship			$\alpha = .764$	.347			
Positive affect			$\alpha = .862$	.509			
Negative affect			$\alpha = .656$	.393			
Restless tense bahavior			$\alpha = .624$	.356			
Positive self-image			$\alpha = .569$	.309			
Social relations			$\alpha = .596$	.231			
Social Isolation			$\alpha = .211$	.088			
Feeling at home			$\alpha = .569$	.279			
Having something to do			$\alpha = .182$	.100			
QUALIDEM (severe)	6.2 (±2.6)	3.7 %	$\alpha = .807$	.195	RMSEA = .07 [90 % CI .00, .14]; CFI = .92; IFI = .93; χ^2 (39) = 48.41, $p = .14$	$r = .216$, $p = .193$ / $r = -.407$, $p = .017$	$r = -.005$, $p = .973$ / n.s.
Care relationship			$\alpha = .711$	.438			
Positive affect			$\alpha = .785$	.479			
Negative affect			$\alpha = .472$	.309			
Restless tense behaviour			$\alpha = .672$	.406			
Social relations			$\alpha = .320$	.139			
Social Isolation			$\alpha = .656$	.397			

sd standard deviation, *n.s.* non significant, *EBI* Extended Barthel Index, *AES* Apathy Evaluation Scale, *RMSEA* Root-mean-square error of approximation, *CI* Confidence interval, *CFI* Comparative fit index, *IFI* Incremental fit index

* Pearson's correlation, ** *t* test, *n.s.* not significant; $^{\#}$ global score

Two items in particular had many missing values: 'marriage' (31) and 'friends' (20). Staff found it difficult to answer these questions if residents were not in a relationship or no longer had any friends. Other missing values were found on the items 'money' (three), 'family' (two), 'mood,' 'person as a whole,' 'ability to do chores,' and 'ability to do things for fun' (one each). The staff needed 3.0 (±2.1) min to complete the QoL-AD.

All QUALIDEM questionnaires could be included in the analysis. A total of 24 missing values were identified and imputed, however, i.e., 0.8 % (0.2 % for mild-to-moderate and 3.7 % for severe dementia) of the possible responses (3,069) (Table 2). The item with the most missing values was 'cuts himself/herself off from environment', with five missing responses. All other 15 items with missing values had a maximum of three missing values. The average time taken to complete the questionnaire was 6.2 (±3.9) for mild-to-moderate and 6.2 (±2.6) minutes for people with severe dementia.

Reliability

In the present study, there was good internal consistency for the subscales 'social interaction' ($\alpha = .719$) and 'feelings and moods' ($\alpha = .770$) and the global QoL of the ADRQL ($\alpha = .870$). However, the subscales 'awareness of self,' 'enjoyment of activity,' and 'response to surrounding' showed a moderate internal consistency (all α .442 – .542). None of the subscale and the global score yielded a sufficient inter-item correlation. Cronbach's α (α=.739) for the global score of the QoL-AD still showed good internal consistency but a weak inter-item correlation (.193). For the sample of people with mild-to-moderate dementia, the QUALIDEM showed moderate-to-good internal consistencies ($\alpha = .569$ 'positive self-image' and 'feeling at home' to $\alpha = .862$ 'positive affect') for seven of the nine subscales. 'Social isolation' ($\alpha = .211$) and 'having something to do' ($\alpha = .182$) showed a trivial internal consistency, however. Both subscales also showed a weak inter-item correlation. The global QoL measured with the QUALIDEM showed good reliability ($\alpha = .875$). For people with severe dementia, there was moderate-to-good internal consistency ($\alpha = .472$ 'negative affect' to $\alpha = .785$ 'positive affect') for five of the six QUALIDEM subscales. The subdomain 'social relation' ($\alpha = .320$) showed a lower internal consistency. However, the mean inter-item correlation is .139. The global QUALIDEM score showed good reliability ($\alpha = .807$).

Validity

Confirmatory factor analysis

For all instruments, the factor analysis indicated a sufficient to good model fit. The ADRQL model fitted the data well (RMSEA = .00 [90 % CI .00, .06], CFI=1.00, IFI = 1.00, χ^2 (25) = 20.31, $p = .35$). The CFA of the QoL-AD resulted in a saturated model, and therefore, fit indices cannot be provided. With the exception of the χ^2, the QUALIDEM for people with mild-to-moderate dementia demonstrated a good model fit (RMSEA = .07 [90 % CI .03, .10], CFI = .90, IFI = .91, χ^2 (99) = 134.33, $p = .01$). The strict version of the QUALIDEM fitted well too (RMSEA = .07 [90 % CI .00, .14], CFI = .92, IFI = .93, χ^2 (39) = 48.41, $p = .14$).

Convergent validity

Regarding convergent validity of the ADRQL, the correlation coefficient between ADRQL global score and functional status (EBI) was .592 (Pearson's r, $p < .001$) and in the hypothesized direction, indicating convergent validity. The ADRQL global score and apathy (AES) correlated negatively. The correlation coefficient was −.654 (Pearson's r, $p < .001$).

The convergent validity of the QoL-AD can be considered as sufficient as well. The QoL-AD global score correlated positively with functional status (EBI) as hypothesized (Pearson's $r = 0.480$, $p < .001$). The QoL-AD global score and apathy (AES) correlated negatively (Pearson's r −.698, $p < .001$).

Convergent validity for the QUALIDEM (mild-to-moderate) was sufficient. A positive correlation was found between the global score and functional status (EBI; Pearson's r .278, $p = .028$). The correlation coefficients ranged from .362 for 'having something to do' to .828 for 'care relationship' (all Pearson's r, $p < .05$). As assumed, the QUALIDEM (mild-to-moderate) global score and apathy (AES) correlated in a negative direction. The correlation coefficient was −.472 (Pearson's r, $p < .001$).

For people with severe dementia, no correlation of the QUALIDEM global score with the EBI was found (Pearson's r .216, $p = .193$). The correlations of the six subscales with the global score were significant, however. The correlation coefficients ranged from .448 for 'social relations' to .748 for 'social isolation' (all Pearson's r, $p < .05$). For this subsample, a negative correlation (Pearson's r −.407, $p = .017$) between the QUALIDEM global score (severe) and apathy (AES) was found, which supports convergent validity.

Discriminant validity

As shown in Table 2, all instruments were not significant correlated with age (all Pearson's r, $p > .05$), which supports discriminant validity as assumed. Also, there were no significant differences in any of the Qol instruments based on the sex of the respondent (all t test, $p > .05$).

Table 3 Quality of life scores

Instrument#	Total sample	Mild-to-moderate dementia	Severe dementia	Group differences##
ADRQL	$n = 104$	$n = 63$	$n = 41$	$n = 104$
Social interaction	78.9 (15.3)	84.5 (17.5)	70.1 (19.1)	$p < .001$**
Awareness of self	67.5 (22.1)	75.3 (18.3)	55.6 (22.4)	$p < .001$**
Feelings and moods	75.4 (19.6)	78.5 (19.0)	70.7 (20.0)	$p = .045$*
Enjoyment of activities	63.9 (26.2)	69.9 (24.2)	54.7 (26.8)	$p = .003$*
Response to surroundings	76.2 (19.2)	78.9 (18.9)	72.1 (19.2)	$p = .083$
Global QoL	73.7 (15.3)	78.7 (17.7)	66.1 (14.6)	$p < .001$**
QoL-AD	$n = 104$	$n = 59$	$n = 38$	
Global QoL	56.8 (11.0)	60.5 (9.6)	51.0 (10.5)	$p < .001$**
QUALIDEM	$n = 104$	$n = 63$	$n = 41$	
Care relationship	n/a	69.5 (19.8)	66.4 (28.8)	n.s.
Positive affect	n/a	78.8 (19.1)	66.1 (25.3)	$p = .002$*
Negative affect	n/a	67.2 (25.6)	62.6 (29.5)	n.s.
Restless tense behavior	n/a	63.5 (27.1)	51.2 (30.2)	$p = .033$*
Positive self-image	n/a	67.3 (27.1)	n/a	n/a
Social relation	n/a	71.8 (18.1)	70.9 (22.7)	n.s.
Social isolation	n/a	61.6 (21.7)	66.1 (30.8)	n.s.
Feeling at home	n/a	74.7 (20.5)	n/a	n/a
Having something to do	n/a	54.0 (29.1)	n/a	n/a
Global QoL	n/a	69.6 (13.7)	64.1 (17.4)	n.s.

Data represent mean (*sd* standard deviation), *n/a* not applicable, *n.s.* not significant

* Significant at 0.05, ** significant at .001, # all scores were standardized 0–100, ## *t* test

Results of the quality of life measurements

All global QoL scores indicate a QoL above 50 (Table 3). The ADRQL scores for the sample of people with mild-to-moderate dementia are the highest with a discrepancy of about nine points related to the QUALIDEM and as high as 18 points in the QoL-AD. In the subsample of people with a severe dementia, again the ADRQL scores indicated the highest QoL. But here, the discrepancy is weaker compared to the QUALIDEM (two points), but still quite high with the QoL-AD (15 points). So in both subsamples, the ADRQL scores indicated the best Qol. The group of residents with a severe cognitive impairment (MMSE < 9) has significant lower QoL scores than the other groups in the ADRQL (ANOVA, $p < .001$), QoL-AD (ANOVA, $p = .011$), and the QUALIDEM (ANOVA, $p = .031$).

Determinants of QoL

The conducted multiple linear regression analysis yielded three significant models. For the ADRQL, the QoL-AD, and the QUALIDEM (whole sample), the significant determinant variable was the AES score (Table 4). These results indicate that higher apathy is significantly ($p < .05$) associated with lower QoL for the ADRQL (β −.535), QoL-AD (β −.411), and QUALIDEM (β −.576).

Discussion

The aim of this paper was to evaluate the psychometric properties and the utility of three QoL instruments (ADRQL, QoL-AD, and QUALIDEM), in order to identify the most appropriate QoL instrument for people with dementia residing in SHA. These instruments best reflect core domains of SHA and other small-scale, homelike care facilities as mentioned above [23]. The findings suggest that all three instruments are adequate in terms of proxy assessment of QoL in this target group.

Sample

The characteristics of the present study sample conform to previous data from SHA residents in Berlin [3, 46] and international small-scale living arrangements [47–49]. It can be concluded to have included typical residents of SHA.

Acceptability

The findings suggest that all three instruments have good acceptability for use in research and care practice. The instruments are easy to administer and take relatively little time to complete (on average between 3 and 7 min).

Table 4 Multiple linear regression model with global QoL scores as dependent variables

	ADRQL		QoL-AD		QUALIDEM (whole sample)	
	Standardized coefficient	*p* value	Standardized coefficient	*p* value	Standardized coefficient	*p* value
Age	−.023	.790	.185	.064	.111	.287
Sex	−.071	.423	− .138	.170	−.199	.058
EBI	.165	.197	.107	.449	−.144	.335
AES	−.535	<.001**	− .411	.003*	−.576	<.001**
GDS	−.043	.677	−. 169	.146	−.069	.572
Constant (unstandardized coefficient)	114.123	<.001**	71.661	<.001**	113.772	<.001**
Adjusted R^2	.431		.329		.222	

EBI Extended Barthel Index, *AES* Apathy Evaluation Scale, *GDS* Global Deterioration Scale

* Significant at 0.05, ** significant at .001

Furthermore, the number of missing items if assessed by proxy (i.e., nursing staff report) is low. Only a few items (related to ‘marriage’ and ‘friends’) on the Qol-AD were perceived as difficult by nurses. This is surprising, given the fact that clear instructions are given in the instrument’s manual on how to rate these questions in case if residents are not married and do not have any friends. The QoL-AD may be more difficult to administer in institutional settings, as it has not been specifically developed for this setting, unlike, for example QUALIDEM. QoL-AD includes items, for example ‘money,’ that do not necessarily is relevant for people living in residential care facilities. In addition to the present findings, Dichter et al. [50] investigated the feasibility of the QUALIDEM, using a qualitative approach. They concluded the QUALIDEM is applicable and practical in long-term care settings, which supports our findings.

Reliability

The findings suggest acceptable levels of internal consistency for QoL-AD and ADRQL and most of the QUALIDEM domains. QUALIDEM was the most recently developed instrument [29, 30]. In the present sample, seven of the nine subscales showed sufficient to good internal consistency ($\alpha > .568$) for people with mild-to-moderate levels of dementia. Two subscales (‘social isolation’ and ‘having something to do’) demonstrated poor internal consistency; however, these subscales only consist of three and two items, respectively. More items would improve the reliability [39] and may, in part, explain the weak internal consistency. A recent study in The Netherlands, which investigated the scalability of QUALIDEM in four sample populations [32], showed slightly different results, indicating that all subscales showed sufficient reliability in people with mild-to-moderate dementia. The differences could be explained by their much large sample size ($n = 759$). Results from German nursing homes indicate a better internal consistency. Again, this sample size was higher ($n = 486$) than in the present study [50].

Validity

The present study confirms the validity of the three instruments measuring QoL in people with dementia, as shown in the results from the CFA. All scales positively correlate with known positive influential factors (i.e., ADL) and negatively with negative influential factors (i.e., apathy), as assumed. No correlation was found concerning age. The proxy assessment of QoL in people with dementia may, however, be biased. Previous studies have shown that the correlation between proxy reports of QoL and rating by people with dementia themselves may be moderate at best, for example varying from .40 [51] to .69 [15]. Furthermore, behavior and attitudes of staff might influence their judgment [19, 52]. In Germany, only Dichter et al. [50] conducted a validation of the QUALIDEM. They found a different structure including the subscales: satisfied behavior, unapproachable and unsatisfied behavior, positive self-image, negative affect, social relations, feeling at home, tense behavior, and having something to do.

Determinants of quality of life

For all instruments, less apathy was associated with better QoL, which is consistent with previous studies [8, 20]. Also, the global QoL for all instruments was associated with better cognitive abilities. However, this phenomenon is usually found in studies applying proxy ratings. People with dementia themselves do not associate their QoL with their cognitive abilities [19, 20].

Implications

This study suggests that there are several instruments available to measure QoL of people with dementia living in small-scale living facilities which have sufficient acceptability, reliability, and validity. Furthermore, they measure domains of QoL that have become increasingly important in these types of facilities, focusing on small-scale, homelike care environments such as SHA. Although the instruments are easy to administer, none of them is superior in terms of reliability and validity. The QoL-AD showed some items which were found difficult to assess, and therefore, this scale may not be appropriate for SHA. The response scale limits the ADRQL. Only to agree or to disagree seems to be not as appropriate as a Likert scale. The findings of acceptability of the QUALIDEM (short time to complete, few missing values, and good practicability [50]) suggest that this instrument is the most appropriate for German SHA. However, further research is needed to develop and improve these existing measurements.

None of the manuals for any of these instruments addressed whether the nurses should rate from a proxy-patient (e.g., to view the situation as the patient would) or a proxy–proxy (proxy was asked to respond on behalf of the patient) perspective [53]. This may bias the comparison of different study results. In future studies, this issues should be clarified, or even investigated, how the point of view influences the ratings.

Limitations

Some limitations regarding this study must be considered. First, the sample size of the study ($n = 104$) was small and consisted of only 39.8 % of all eligible residents in SHA. Despite the fact that this is only a subset, residents in the present study do not differ significantly in terms of basic socio-demographic data and represent a typical population of SHA [3, 46]. Although the characteristics of the non-responder are unknown, a sample bias therefore is not expectable. Furthermore, only a limited number of items per factor could be included in the CFA to investigate construct validity. It would have been better to use more factors to validate the model. All identified instruments are not eligible to be included into economic evaluations, like a newer version of the DEMQOL (measuring DEMentia-specific Quality of Life) does [54].

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Conflict of interest None.

References

1. Loe, M., & Moore, C. D. (2012). From nursing home to green house: Changing contexts of elder care in the United States. *Journal of Applied Gerontology, 31*(6), 755–763.
2. Verbeek, H., Rossum, Ev, Zwakhalen, S. M. G., Kempen, G. I. J. M., & Hamers, J. P. H. (2009). Small, homelike care environments for older people with dementia: A literature review. *International Psychogeriatrics, 21*(02), 252–264.
3. Wolf-Ostermann, K., Worch, A., Fischer, T., Wulff, I., & Gräske, J. (2012). Health outcomes and quality of life of residents of shared-housing arrangements compared to residents of special care units - results of the Berlin DeWeGE-study. *Journal of Clinical Nursing, 21*(21–22), 3047–3060.
4. Fischer, T., Worch, A., Nordheim, J., Wulff, I., Gräske, J., Meye, S., et al. (2011). Ambulant betreute Wohngemeinschaften für alte, pflegebedürftige Menschen - Merkmale, Entwicklungen und Einflussfaktoren [Shared-housing arrangements for care-dependent older persons - characteristics, development and drivers]. *Pflege, 23*(2), 97–109.
5. Calkins, M. P. (2001). *Creating successful dementia care settings*. Baltimore: Health Professions Press.
6. Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., de Vugt, M., et al. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging and Mental Health, 12*(1), 14–29.
7. Volicer, L. (2007). Goals of care in advanced dementia: Quality of life, dignity and comfort. *The Journal of Nutrition, Health and Aging, 11*(6), 481.
8. Ettema, T. P., Dröes, R.-M., Lange, Jd, Mellenbergh, G. J., & Ribbe, M. W. (2005). A review of quality of life instruments used in dementia. *Quality of Life Research, 14*(3), 675–686.
9. Barofsky, I. (2012). Can quality or quality-of-life be defined? *Quality of Life Research, 21*(4), 625–631.
10. Rabins, P. V., & Black, B. S. (2007). Measuring quality of life in dementia: purposes, goals, challenges and progress. *International Psychogeriatrics, 19*(03), 401–407.
11. Traynor, V., Inoue, K., & Crookes, P. (2011). Literature review: Understanding nursing competence in dementia care. *Journal of Clinical Nursing, 20*(13–14), 1948–1960.
12. Schölzel-Dorenbos, C. J. M., Meeuwsen, E. J., & Rikkert, M. G. M. O. (2010). Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the hierarchy model of needs in dementia. *Aging and Mental Health, 14*(1), 113–119.
13. Selai, C. (2001). Assessing quality of life in dementia. *Medical Care, 39*(8), 753–755.
14. Trigg, R., Skevington, S. M., & Jones, R. W. (2007). How can we best assess the quality of life of people with dementia? The bath assessment of subjective quality of life in dementia (BASQID). *The Gerontologist, 47*(6), 789–797.
15. Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T., et al. (2003). Whose quality of life is it anyway? The validity and reliability of the quality of life-Alzheimer's disease (QoL-AD) Scale. *Alzheimer Disease and Associated Disorders, 17*(4), 201–208.
16. Huang, H.-L., Chang, M. Y., Tang, J. S.-H., Chiu, Y.-C., & Weng, L.-C. (2009). Determinants of the discrepancy in patient- and caregiver-rated quality of life for persons with dementia. *Journal of Clinical Nursing, 18*(22), 3107–3118.

17. Fuh, J.-L., & Wang, S.-J. (2006). Assessing quality of life in Taiwanese patients with Altzheimer′s disease. *International Journal of Geriatric Psychiatry, 21*, 103–107.
18. Tatsumi, H., Nakaaki, S., Torii, K., Shinagawa, Y., Watanabe, N., Murata, Y., et al. (2009). Neuropsychiatric symptoms predict change in quality of life of Alzheimer disease patients: A two-year follow-up study. *Psychiatry and Clinical Neurosciences, 63*(3), 374–384.
19. Gräske, J., Fischer, T., Kuhlmey, A., & Wolf-Ostermann, K. (2012). Quality of life in dementia care - differences in quality of life measurements performed by residents with dementia and by nursing staff. *Aging and Mental Health, 16*(7), 818–827.
20. Banerjee, S., Samsi, K., Petrie, C. D., Alvir, J., Treglia, M., Schwam, E. M., et al. (2009). What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *International Journal of Geriatric Psychiatry, 24*(1), 15–24.
21. Adler, E., & Resnick, B. (2010). Reliability and validity of the dementia quality of life measure in nursing home residents. *Western Journal of Nursing Research, 32*(5), 686–704.
22. Edelman, P., Fulton, B., Kuhn, D., & Chang, C.-H. (2005). A comparison of three methods of measuring dementia-specific quality of life: Perspectives of residents, staff, and observers. *The Gerontologist, 45*(Suppl 1), 27–36.
23. Gräske, J., Fischer, T., Kuhlmey, A., & Wolf-Ostermann, K. (2012). Dementia-specific quality of life instruments and their appropriateness in shared-housing arrangements - a literature study. *Geriatric Nursing, 33*(3), 204–216.
24. Lohr, K. N. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research, 11*(3), 193–205.
25. Walters, S. J. (2009). *Qualtiy of life outcomes in clinical trials and health-care evaluation—a practical guide to analysis and interpretation* (1st Ed.). West Sussex: Wiley.
26. Rabins, P. V., Kasper, J. D., Kleinman, L., Black, B. S., & Patrick, D. L. (1999). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer disease. *Journal of Mental Health and Aging, 5*(1), 33–48.
27. Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64*(3), 510–519.
28. Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21–32.
29. Ettema, T. P., Dröes, R.-M., Lange, Jd, Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: Development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *International Journal of Geriatric Psychiatry, 22*(6), 549–556.
30. Ettema, T. P., Dröes, R.-M., Lange, Jd, Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: Development and evaluation of a dementia specific quality of life instrument - validation. *International Journal of Geriatric Psychiatry, 22*(5), 424–430.
31. Weyerer, S., & Schäufele, M. (2006). Commentary: Medical care for nursing home residents: National perspectives in international context. In H.-W. Wahl, H. Brenner, & D. Rothenbacher (Eds.), *The many faces of health, competence and well-being in old age*. Dordrecht: Springer.
32. Bouman, A. I. E., Ettema, T. P., Wetzels, R. B., van Beek, A. P. A., de Lange, J., & Dröes, R. M. (2011). Evaluation of Qualidem: a dementia-specific quality of life instrument for persons with dementia in residential settings; scalability and reliability of subscales in four Dutch field surveys. *International Journal of Geriatric Psychiatry, 26*(7), 711–722.
33. Wetzels, R. B., Zuidema, S. U., Jonghe, J F Md, Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Determinants of quality of life in nursing home residents with dementia. *Dementia and Geriatric Cognitive Disordders, 29*, 189–197.
34. Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state” : A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189–198.
35. Reisberg, B., Ferris, S., de Leon, M., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry, 139*(9), 1136–1139.
36. Prosiegel, M., Böttger, S., Schenk, T., König, N., Marolf, M., Vaney, C., et al. (1996). Der Erweiterte Barthel-Index (EBI) - eine neue Skala zur Erfassung von Fähigkeitsstörungen bei neurologischen Patienten [The Extended Barthel Index - a new scale for the assessment of disability in neurological patients.]. *Neurologie and Rehabilitation, 1*, 7–13.
37. Marin, R. S., Biedrzycki, R. C., & Firinciogullari, S. (1991). Reliability and validity of the apathy evaluation scale. *Psychiatry Research, 38*(2), 143–162.
38. Fitzpatrick, R., Davey, C., Buxton, M. J., Jones, D. R. (1998). Evaluating patient-based outcomes measures for use in clinical trials. *Health Technology Assessment*, *2*(14), 1–76.
39. Fayers, P., Machin, D. (2007). *Quality of life: The assessment, analysis and interpretation of patient-reported outcomes*. (2nd ed). Chichester: Wiley.
40. Arbuckle, J. L. (2005). *Amos 6.0 update to the amos user's guide*. Chicago: SPSS, Inc.
41. Bandalos, D. L., & Finney, S. J. (2001). Item parceling issues in structural equation modeling. In G. A. Marcoulides & R. E. Schumacker (Eds.), *Advanced structural equation modeling: New developments and techniques*. Mahwah: Lawrence Erlbaum Associates, Inc.
42. Little, T. D., Cunningham, W. A., Shahar, G., & Widaman, K. F. (2002). To parcel or not to parcel: Exploring the question, weighing the merits. *Structural Equation Modeling: A Multidisciplinary Journal, 9*(2), 151–173.
43. Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., López-Pousa, S., & Vilalta-Franch, J. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. *International Journal of Geriatric Psychiatry, 24*(6), 585–594.
44. Hoe, J., Katona, C., Roch, B., & Livingston, G. (2005). Use of the QOL-AD for measuring quality of life in people with severe dementia—the LASER-AD study. *Age and Ageing, 34*(2), 130–135.
45. Polit, D., & Beck, C. (2008). *Nursing research. gernerating and assessing evidence for nursing practice* (8th ed.). Philadelphia: Wolters Kluwer.
46. Gräske, J., Wulff, I., Fischer, T., Meye, S., Worch, A., & Wolf-Ostermann, K. (2011). Ambulant betreute Wohngemeinschaften für ältere, pflegebedürftige Menschen - Unterstützung von Angehörigen und Ehrenamtlichen [Shared-housing arrangements for care dependent older persons. Support from family members and volunteers]. *Pflegezeitschrift*, *64*(11), 664–669.
47. Verbeek, H., Zwakhalen, S. M. G., van Rossum, E., Ambergen, T., Kempen, G. I. J. M., & Hamers, J. P. H. (2010). Dementia care redesigned: effects of small-scale living facilities on residents, their family caregivers, and staff. *Journal of the American Medical Directors Association, 11*(9), 662–670.
48. Funaki, Y., Kaneko, F., & Okamura, H. (2005). Study of factors associated with changes in quality of life of demented elderly persons in group homes. *Scandinavian Journal of Occupational Therapy, 12*, 4–9.
49. Kane, R. A., Lum, T. Y., Cutler, L. J., Degenholtz, H. B., & Yu, T. (2007). Resident outcomes in small-house nursing homes: A

longitudinal evaluation of the initial green house program. *Journal of the American Geriatrics Society, 55*(6), 832–839.

50. Dichter, M., Bartholomeyczik, S., Nordheim, J., Achterberg, W., & Halek, M. (2011). Validity, reliability, and feasibility of a quality of life questionnaire for people with dementia. *Zeitschrift für Gerontologie und Geriatrie, 44*(6), 405–410.
51. Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2000). Quality of life in Alzheimer's disease: Patient and caregiver reports. In S. M. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in Alzheimer's disease* (pp. 17–30). New York: Springer.
52. Spector, A., & Orrell, M. (2006). Quality of life (QoL) in Dementia: A comparison of the perceptions of people with dementia and care staff in residential homes. *Alzheimer Disease and Associated Disorders, 20*(3), 160–165.
53. Pickard, A. S., & Knight, S. J. (2005). Proxy evaluation of health-related quality of life: A conceptual framework for understanding multiple proxy perspectives. *Medical Care, 43*(5), 493–499.
54. Rowen, D., Mulhern, B., Banerjee, S., van Hout, B., Young, T. A., Knapp, M., et al. (2012). Estimating preference-based single index measures for dementia using DEMQOL and DEMQOL-Proxy. *Value in health : The Journal of the INTERNATIONAL Society for Pharmacoeconomics and Outcomes Research, 15*(2), 346–356.