Aus dem Institut für Medizinische Soziologie und Rehabilitationswissenschaft
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DISSERTATION

Longitudinale Messung der Lebensqualität bei Menschen mit
Demenz in Pflegeheimen

Longitudinal assessment of quality of life in people with dementia
living in nursing homes

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von

Stefan Junge

aus Chemnitz

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Abkürzungsverzeichnis

ADL	Activities of Daily Living
ADRQL	Alzheimer's Disease Related Quality of Life
AIC	Akaike's Information Criterion
AR	Autoregression
CI	Confidence Interval
FAST	Functional Assessment Staging
GDS	Geriatric Depression Scale
PwD	People with Dementia
QoL	Quality of Life

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Abstract (deutsch)

<u>Hintergrund und Stand der Wissenschaft:</u> Die Lebensqualität (QoL) spielt eine wichtige Rolle bei Menschen mit Demenz (PwD). Um die QoL zu verbessern, ist es wichtig, diese situationsnah, umfassend und genau zu messen. Viele der bestehenden Instrumente zur Messung von QoL, sind zu lang, um diese in der Situation und zu häufigen Zeitpunkten zu erfassen. Wir haben in situ stattfindende und wiederholte Kurzmessungen der QoL zu wiederholten Zeitpunkten gemessen und untersucht, in welcher Beziehung diese Messungen zur umfassenden Messung von QoL und Faktoren stehen, die mit QoL assoziiert sind.

<u>Methoden:</u> Diese Studie beinhaltete eine „umfassende" Bewertung der QoL zu Studienbeginn (QUALIDEM; 37 Items), welche um eine Version des QUALIDEM ergänzt wurde, die aus acht Items bestand und die mehrfach in der Woche über mehrere Wochen appliziert wurde („momentane" QoL). Insgesamt wurde die momentane QoL zu Studienbeginn bei 150 Bewohnenden aus 10 Pflegeeinrichtungen erhoben. Die momentane QoL wurde wiederholt durch eine Pflegekraft mit Tablet-Computern gemessen. Darüber hinaus wurden umfassende QoL, Geschlecht, Alter, Aktivitäten des täglichen Lebens (Barthel Index), Demenzstatus (FAST) und Depressivität (GDS) erfasst und in univariaten und multivariaten Mehrebenenmodellen mit der momentanen QoL in Beziehung gesetzt. Zur Schätzung der Reliabilität der kurzen 8-Item Version des QUALIDEM wurde Cronbach's Alpha berechnet.

<u>Ergebnisse:</u> Die momentane QoL zeigte zu verschiedenen Zeitpunkten (Anzahl Zeitpunkte Median = 8; Spannweite 1-28) eine gute interne Konsistenz mit einem Cronbach's Alpha von 0,86 bis 0,93. In unserer multiplen Analyse der Assoziationen war die momentane QoL signifikant mit der GDS (B = -, 13; CI = -,19/-,06) und der umfassenden QoL (B = ,14; CI =,08/,20) verbunden. In einer Subskalenanalyse zeigten die Subskalen „Unruhe", „positiver Affekt", „negativer Affekt" und „soziale Beziehungen" signifikante Assoziationen mit der momentanen, in situ gemessenen QoL (alle $p < 0,05$).

<u>Diskussion:</u> Wir fanden, dass die momentane QoL mit den umfassenden Messungen der QoL und depressiven Symptomen bei PwD von stationären Pflegeeinrichtungen in Beziehung stand. Eine breitere Verwendung von Tablet-basierten Bewertungen bei wiederholten QoL-Messungen könnte dem Zeitmanagement des Pflegepersonals entgegenkommen und die Pflegequalität und die Kommunikation zwischen Pflegenden und PwD verbessern.

Abstract (english)

Background and State of Research: Quality of Life (QoL) plays an important role in people with dementia (PwD. In order to better QoL in PwD it is important to evaluate QoL in the moment and comprehensively. Most of the existing QoL instruments are not suitable to assess QoL in a high frequency at several time-points. Therefore, we took a further look on QoL measured at several time-points and how momentary QoL is related to comprehensive QoL and factors that are associated with dementia and QoL.

Methods: To validate an eight-item version of QUALIDEM we assess a momentary QoL at baseline, which was repeatedly measured by nurses with tablet computers. In our study 150 PwD residing in 10 long-term care-facilities were examined. Comprehensive QoL, gender, age, activities of daily living (Barthel Index), Functional Status (FAST), and depressive symptoms (GDS) have been assessed and subsequently evaluated in univariate and multivariate analyses. To evaluate reliability of the short eight-item of QUALIDEM we calculated Cronbach's alpha.

Results: Momentary and comprehensive QoL showed good internal consistency with a Cronbach's alpha of .86 to .93, at different time-points. In our multiple analysis of associations of momentary QoL and comprehensive QoL, momentary QoL was significantly related to GDS (B=-.13, CI=-.19/-.06) and comprehensive QoL (B=.14, CI=.08/.20). The subscales ('restlessness', 'positive affect', 'negative affect' and 'social relationships') of QUALIDEM which include multiple items were examined and showed significant positive associations with momentary QoL (all p<.05).

Discussion: We found momentary QoL, was associated with comprehensive QoL and depressive symptoms in PwD. Extensive use of tablet-based QoL assessment using the short eight-item version of QUALIDEM may improve quality of care and communication by the nursing staff and PwD living in nursing homes.(1)

1 Introduction and state of research

1.1 Relevance of dementia and the assessment of quality of life

According to the World Alzheimer report 2019, worldwide over 50 million people are diagnosed with dementia.(2) In Germany the prevalence of dementia in people living in nursing homes that are older than 65 is 19 times more than the prevalence of people ages 65+ living in the community.(3) Largely the prevalence of dementia is increasing, markedly in countries with low and middle incomes. It is a health- and social-care priority for many high-income countries like Germany, United Kingdom and the United States. In Germany a quarter of the PwD live in nursing homes.(4), while in the United States a quarter to a half, and in the United Kingdom 39 % of PwD reside in nursing homes.(5, 6) In contrast the incidence rates were stable or had been decreased.(7, 8)

Changes in demography will lead to an immense increase in the number of people with dementia.(7) Dementia is a clinical syndrome caused by neurodegeneration (Alzheimer's disease, vascular dementia, Lewy body, and frontotemporal dementia). characterized by a progressive deterioration in cognitive ability and capacity for independent living. In 2050 approximately 152 million PwD will live worldwide.(2) Due to it is not possible to cure dementia, the main aim of caring, nursing and drug treatment is the upgrading and preservation of the QoL of PwD, and delaying the progression of dementia to improve the care situation for PwD and care takers.(9) In recent decades, several dementia- specific QoL measures for research have been developed and evaluated. Literature suggests that activity engagement is important because it may give dementia patients pleasure and enjoyment, provides a sense of connection and belonging, and helps them to maintain a sense of autonomy and personal identity.(10) Cooper et al. (2013) showed in their systematic review, that none of the examined studies showed a significant effect of pharmacologic interventions on QoL in PwD.(11) Whereas the non-pharmacological interventions indicated that a coping strategy-based family carer therapy increased QoL in PwD living at home. Group Cognitive Stimulation Therapy was identified as the only sufficient intervention that increased QoL in PwD living in nursing homes. Although most studies did not show longer-term effects of interventions. Thus, further studies were suggested to examine effects on QoL after the period of intervention.(12)

1.2 Assessment of quality of life

1.2.1 Instruments to assess quality of life

Whereas responsiveness of measuring QoL over time is limited generally, Dementia specific QoL measures such as Quality of Life for Dementia (QOL-D), Quality of Life in Alzheimer's Disease (QOL-AD), Dementia Quality of Life instrument (D-QOL) and The Cornell–Brown Scale for Quality of Life in Dementia did not show a clearly responsiveness over time.(13) Until 2007 in German residential settings, no dementia specific QoL measurement tool was available to assess QoL of all residents, including the very severely demented.(14)

Some instruments to measure QoL cover mainly functional and cognitive abilities, which is used to evaluate the health status rather than the QoL of PwD. As dementia ultimately leads to a decrease of cognitive and physical abilities, psychosocial aspects such as social relations, the care relationships and residents in a nursing home are more relevant territories for assessing QoL.(15) Ettema et. al (2007) identified the Quality of Life in Dementia (QUALIDEM) in the appropriate databases as the instrument with the best focus on psychological aspects of QoL and psychometric properties in PwD with light and severe dementia.(16) Although multidimensionality and domains (subscales) are suitable using it as an dementia specific QoL assessment tool in a longitudinal study (17), it has not been evaluated how responsive measures are over time.(18) Gräske et al. (2014) compared the three accepted QoL for PwD instruments: Alzheimer's Disease Related Quality of Life (ADRQL), Quality of Life Alzheimer's Diseases (QoL-AD) and QUALIDEM. They showed that QUALIDEM was one of the preferred instruments to assess QoL in people with dementia in shared housing arrangements, providing the best acceptability that has been defined as a shorter completion time and a higher item completion rate.(19) As the original QUALIDEM offers 37-items to examine QoL in PwD with mild and severe symptoms, 18 items are suggested to use in PwD with severe symptoms.(20)

1.2.2 Ecological momentary assessment

Ecological momentary assessment is a method to intensively examine variables over time in longitudinal studies. Participants or proxies report a specific status in the moment. Questions of a surveys can be quantitative or qualitative and may be assessed on various devices. Mostly tablet computers or smartphones are used to assess data and capture it.(21)

Ecological momentary assessment is designed to assess variables on a daily base taken all kinds of environmental, physical and psychological factors into account. It is a standard procedure in intensive care units where electrocardiogram or the blood pressure needs to be measured in the moment. Further on in the psychological field it is helpful as well. The advantage of using an electronic device during the session, instead of using pen and paper, is that less time passes between taken the note and the situation itself in which the event occurred.

The elapsing time itself is a new variable that can be examined as well, thus our data extends and may offer new conclusions, such as which variable is answered in the most or least amount of time. Ecological momentary assessment may help to find intra-individual relationships between patients and observers and increase compliance of patients. The accuracy compared to classic comprehensive studies may be better and bias might be minimized as well.

Another aspect is the reliability and validity of data. Whereas reliability is used to calculate the size of errors of measures, having a good test re-test reliability ensures that the measurements obtained in one sitting are both representative and stable over time. Test-retest reliability, and parallel-forms reliability can be used in mixed-methods data. Test Re-test reliability is understood as internal validity of an assessment to examine if a tested variable is stable over time using the Cronbach's alpha formula.(22) Thus, a good measure tool provides the same results in various measures across time and offers consistent results, which imply variables that are very likely positively or negatively related to each other.

1.2.1   Proxy versus self-reporting

Dementia- specific QoL measures can be differentiated into self-report and proxy- report instruments. Self-reports from PwD are accepted as the best way to understand the experience of PwD, but may be influenced by their cognitive status and limitations.(23) Thus, proxy reports are helpful to examine QoL in PwD with severe dementia, whereas communication is impaired. Studies have indicated different levels of agreement between proxy and resident reports, although proxy report is an efficient way to obtain data on persons with dementia.(24) One may argue against ratings by professionals as they often report lower QOL than the people themselves. This phenomenon often referred to as the disability paradox.(25)

In longitudinal studies, it may have benefits in PwD to simultaneously use proxy ratings. Progressive deterioration of PwD and being unable to report adequately are associated with missing data. Smith et al. (2005) showed the use of proxy reports reduced bias over time and led to less missing data. (26)

1.2.2 Factors associated with quality of life and state of research

Systematic reviews pointed out that depressive symptoms, lower cognitive status and less activities of daily living had been associated with a lower QoL and mood, whereas reflecting relationships, social engagement and functional ability were associated with a better QoL.(27, 28) QUALIDEM offers 9 subscales including 37 items. Other studies examined how those subscales are related to known dementia- relevant factors such as Geriatric Depression Scale (GDS), Functional Assessment Staging (FAST), age, and Barthel Index. Klapwijk et al. (2016) found associations between the QUALIDEM subscale 'social isolation' and age and associations between the QUALIDEM subscale 'positive affect' and psychiatric disorders. Furthermore, QoL in PwD was independently associated with age, Barthel Index, dementia severity, pain, other psychiatric disorders and pulmonary diseases.(29) A study by van Dam et al. (2018) of a randomized-double-blind placebo-controlled crossover trial in PwD underlines the associations of Barthel Index and QoL in their baseline measures.(30) As the evaluation of QoL in PwD has become progressively valued, especially as a tool to assess the quality of care. Multiple instruments have been developed to assess QoL in PwD showing a broad range of reliability estimates from weak to good across studies and settings. Predictive validity has not been tested on a large and broader scale, more stringent testing of QoL has been suggested.(31)

As literature suggests, we captured known factors associated with QoL and dementia such as gender, age, GDS, FAST, Barthel Index and the subscales of QUALIDEM. Although many established QoL instruments allow a comprehensive assessment of the QoL in PwD, momentary variations across time may be uncaptured. Thus, further examinations of QoL at several time-points were necessary to point out how QoL would vary across time.

1.3 Aims of the study

Our aims were:
- Validating a short eight-item version of the QoL assessment tool QUALIDEM to measure momentary QoL at several time-points and a comprehensive QoL (37 items of QUALIDEM) in PwD living in nursing homes.
- Using tablet computers to capture momentary QoL on a comprehensive level across time and find out how related factors are associated with.

- Assessing known factors that were associated with QoL such as gender, age, Barthel Index, FAST and GDS.
- Assessing subscales of QUALIDEM and their relation to momentary QoL
- Testing reliability of our data over time.

Examining the relationship between the comprehensive 37-item version of QUALIDEM assessed at one time-point and the short eight-item version of QUALIDEM assessed at several time-points might help to understand QoL better in PwD living in nursing homes, whereas the following hypothesizes were assumed:

- A positive association of momentary QoL with comprehensive QoL;
- An association of momentary QoL with age, gender, time trend and variation between nursing homes
- A positive association of Barthel Index and FAST with momentary QoL
- A negative association of GDS with momentary QoL
- A relation between momentary QoL and their comprehensive QUALIDEM subscales: 'care relationship', 'positive affect', 'negative affect', 'restlessness', 'positive self-image', 'social relationships', 'social isolation', 'feeling at home' and 'having something to do'

2 Methods

2.1 Study design and procedure

The present investigation was part of the PflegeTab (*engl.* CareTab) study. PflegeTab was accomplished during an eight-week period and examined various factors that are associated with QoL in PwD living in nursing homes. The nursing staff of ten nursing homes proceeded the proxy ratings using specially programmed tablet apps for that study. The app was designed to activate the residents of nursing homes and to measure their QoL during the intervention period, at baseline and after the intervention period. Residents proceeded the activation 3 times per week for up to 30 minutes. Before and after the intervention the comprehensive QoL was assessed with the long 37-item version of QUALIDEM. Our analyses referring to the article were limited to the baseline measurements and excluded the intervention period. (Table1) Based on the main study of

PflegeTab we planned a sample size of N = 240 with 10 clusters (nursing homes). In eight nursing homes a total sample size of N= 150 could be archieved in our cluster randomized trial, whereas each nursing home was a cluster. Because the baseline momentary QoL and comprehensive QoL could not be imputed 13 participants were excluded in the study of the referred article by Junge et al. (2020).(1) The effect size of the sample size was medium with a Cohen's d=0.5 between the two arms at the beginning of the study at baseline. (α=0.05; 1 - β=0.80; 20% dropout rate; between cluster variance ICC=0.005; G*Power 3.1). The PwD that were included in the study were diagnosed with Alzheimer's disease, vascular dementia, and unspecified dementia, according to the (International Statistical Classification of Diseases and Related Health Problems- ICD-10: F00-F03). Except of F10.1; F17.1; F17.2; F32.2 and F32.3, all participants with serious chronic psychiatric diagnoses from F10-29 were excluded. A resident who did not live longer than 4 weeks in a nursing home would also be excluded, which led to 203 contacted participants or their proxies, of which 163 PwD participated in the PflegeTab study.

2.2   Measures

The first version of QUALIDEM consist 37-items, which included the nine domains of QoL: 'positive affect', 'negative affect', 'restlessness', 'positive self-image', 'social isolation', 'care relationship', 'feeling at home', 'social relationships' and 'having something to do'. Whereas domains can be understood as subscales.(32) The second version of the QUALIDEM comprises 18 items covering six domains of QoL: 'care relationship', 'positive affect', 'negative affect', 'restlessness', 'social relationships' and 'social isolation'. Due to the subscales: 'positive self-image', 'feeling at home' and 'having something to do' cannot be assessed in people with very severe dementia, less items were applied to assess QoL in PwD with severe dementia. For the first time in our study, an eight-item version QUALIDEM has been introduced, which only included the four subscales: 'negative affect', 'positive affect' 'restlessness', and 'social relationships'. In our study we did not take a further look on the intervention itself but on the baseline measures at beginning of the intervention within an eight-week period. We took into account the comprehensive and the momentary QoL, whereas comprehensive QoL was measured with the long 37-item version of QUALIDEM and for the momentary QoL was measured with the newly established short eight-item version of QUALIDEM. In our main analysis we created a sum score for the 37 items to measure the comprehensive QoL, whereas a sum score for the 8 items has been

created to measure the momentary QoL. According to literature we identified determinants of QoL in order to elect items that represent the 9 subscales of QUALIDEM.(33-35)

The momentary QoL was assessed with tablet computers at several time-points with only eight items of QUALIDEM. The eight items belonged to four of the subscales. Whereas the comprehensive QoL, GDS, Barthel Index and FAST were assessed at one time-point at the beginning of our study. Our nine subscales included all 37 items, whereas 7 items belong to the subscale 'care relationship'. The subscale 'positive affect' and 'social relationship' were represented by 6 items each. 'Negative affect', 'restlessness', 'social isolation' and 'positive self-image' was represented by 3 items each. The subscale 'feeling at home' was represented by 4 items and the subscale 'having something to do' was represented by 3 items. (Table 5). The nine subscales represent more than one item, because they are sum scores across the items, in a Likert scale with 4 responses from never (0), rarely (1), and sometimes (2) to frequently (3). The median session per person was 8 and ranged from 1 to 28 sessions.

The functional status was assessed with the Barthel Index, which represents the ability to perform activities of daily living. Scores are possible from 0 (complete assistance of activities of daily living) to 100 (no assistance during activities of daily living) and ranged in our study from 0 to 95.

The stage of dementia was measured with the Functional Assessment Staging (FAST), which was designed to assess the stage of dementia in each individual. Scoring from 1 to 16 this tool allowed us to categorize from stage 1 (no impairment) to stage 7 (very severe cognitive decline).(36)

Depressive symptoms were assessed with the 15-item version of the Geriatric Depression Scale (GDS). 10 items were interpreted as depressive symptoms when answered positively and 5 items were interpreted as depressive symptom if answered negatively, whereas the shorter 15-item version of GDS showed valid and reliable results compared to the longer 30-item version.(37)

2.3 Statistical Analysis

All associations of momentary and comprehensive QoL were analysed with linear mixed models on three levels at baseline. Momentary QoL mean scores (Level 1) were regressed on momentary time trend (level 1), comprehensive QoL, gender, age, functional and cognitive status, and depressive symptoms (level 2). Level 3 variable was defined by each nursing home, which we

used as a clustering variable. To evaluate our multivariate models, we examined the trends analyzing the graphs and compared the AIC values, in order to estimate if the models fit.

All variables have been standardized with coefficients that vary between -1 and 1, in order to define them as beta coefficients. All analyses of our data were executed with MIXED procedure in SPSS (IBM SPSS Statistics for Windows, Version 25.0, released 2017. Armonk, NY: IBM Corp.).(1) Momentary QoL mean scores (level 1) were regressed on momentary time trend (level 1), comprehensive QoL, gender, age, functional and cognitive status, and depressive symptoms (level 2).

Level 3 variable was defined by each nursing home, which we used as a clustering variable.

Linear effect and variables of gender, age, functional and cognitive status, and depressive symptoms were fixed, whereas the variance between the nursing homes was set random in all of our models.

Intercepts could vary across PwD and nursing homes (intercept only model; variance components). According to Bruce et al. (2008) and the attached article by Junge et al. (2020) time variables were considered for autocorrelation, where smaller values of the AIC (Akaike's Information Criterion) indicate a better fit: $AIC_{autoregressive}=6272$ and $AIC_{unstructured}=6544$ that would not converge; $AIC_{identity}=6617$; $AIC_{variance\ components}=6622$.(1, 21)

2.4   Internal consistency

Internal consistency is mostly measured with Cronbach's alpha to find correlations between two items. In our case we examined Cronbach's alpha at all time-points where momentary QoL has been assessed in order to show how momentary QoL and comprehensive QoL are related to each other and if these two scales would measure accurately, which is shown in the attached article by Junge et al. (2020) in Supplementary Table S1.

Cronbach's alpha ranges between a negative infinite value and one.

In case there were dichotomous items we have used the Kuder-Richardson Reliability Coefficients KR20 in ranging from 0 to 1. Internal consistency was considered as excellent if Cronbach's alpha was $\alpha \geq .90$, as good if $\alpha \geq .80$ and as acceptable if $\alpha \geq .70$. If α was between .60 and .70 it was considered as questionable. Whereas $0.5 \leq \alpha < 0.6$ was defined as poor and $\alpha < 0.5$ was determined as unacceptable as unacceptable.(38) The aim of that examination was to find if QUALIDEM would find high relations between each item.

2.5 Test-retest reliability

Test-retest reliability, tests the reliability of the test with itself. It is used to measure the same test under the same conditions on the same item at different time points. It helps to evaluate monitoring in a clinical setting or to evaluate the reliability of psychological test as well. (39)

In our study we measured the test-retest reliability in 2 lagged momentary QoL variables (lag 1, lag 2) which can be found in the Supplementary Table S2 in the attached article by Junge et al. (2020).

The conditions were the same within the three levels of the hierarchy of our multiple longitudinal study. Lag 1 specifies the momentary QoL in a session onto momentary QoL in the session before a session. Thus, lag 2 refers to the momentary QoL in a session onto momentary QoL two sessions before that session. Because it is not likely the test-retest reliability will be excellent, a variability can be observed. This variability can be rather an intra-individual variability and intra-observer variability.

3 Results

3.1 Descriptive statistics

In our study, 75% of the sample group were women. In both genders the mean age was 84.9 (SD=7.1) years (Table 1). Up to 29 time-points, sessions were done with a mean number of sessions of 8.6 (SD=6.3).

The mean GDS score was 3.9 (SD=2.9), mean Barthel Index score was 54.1 (SD=26.3), mean FAST score was 9.0 (SD = 1.9), mean Comprehensive QoL was 83.3 (SD=14.9), whereas the mean momentary QoL was 5.4 (SD=1.2).

Table 1: Descriptive statistics

Scale	Mean (SD)	Empirical range
Age, years	84.9 (7.1)	53-100
Women, %	75	
Depressive symptoms, GDS	3.9 (2.9)	0-15
Functional status, Barthel Index/ADL	54.1 (26.3)	0-95
Stage of dementia, FAST	9.0 (1.9)	4-16
Baseline momentary QoL	5.4 (1.2)	1.6-7.0
Baseline comprehensive QoL (sum score)	83.3 (14.9)	43-115

Note. SD=standard deviation. GDS=Geriatric Depression Scale; FAST= Functional Assessment Staging; ADL= Activity

3.2 Internal Consistency

With a Cronbach's alpha of α=.86 the comprehensive sum scale of the QUALIDEM was good, whereas the internal consistency of the eight-item momentary QoL was excellent with a Cronbach's alpha of α=.89. PwD had a median total number of 8 sessions to measure momentary QoL in which Cronbach's alpha ranged from α=.88 to α=.93. Thus, a decent reliability during each session could be shown (Table 2).

The internal consistency of all time points can be found in Junge et al. (2020) Supplementary Table S1.

Table 2: Internal consistency of momentary QoL by time-point

Time-point	0	1	2	3	4	5	6	7	8	9
Cronbachs' alpha	.89	.88	.88	.88	.92	.90	.91	.93	.93	.92

*Table 2 is based on Table S1 in the article published by Junge et al. (2020)(1)

3.3 Univariate Associations

A significant association of QoL could not be found in time-points (session, linear) (B=.05, CI=-.01/.11, *p*=.123), age (B=-.06, CI=-.12/.01, *p*=.081), gender (B=.01, CI=-.05/.07, *p*=.72), Barthel Index (B=-.006, CI=-.07/.06, *p*=.86), and FAST score (B=.04, CI=-.03/.10, *p*<.240; Table 3). Whereas momentary QoL was significantly positively related to comprehensive QoL (B=.17, CI=.11/.23, *p*<.001). Another significance was found between depressive symptoms and momentary QoL (B=-.16, CI=-.22/-.10, *p*<.001), where GDS was negatively related to momentary QoL.

In order to include random effects in our univariate model, the regression of momentary QoL on comprehensive QoL was measured. With B=.90 (CI=.84/.96, *p*<.001) the random variance measurements of each time-point between individuals (autoregression, diagonal) was significant. Correspondingly the correlation between time-points of QoL measurement was significantly related as shown in our autoregression model (autoregression, rho; B=.39, CI=.35/.43, *p*<.001; Table 3).

Thus a higher rating in a session was related to a higher rating in the following session. However, the random variance between facilities was not significant in the univariate model (B=.08, CI=.03/.22, *p*=.062; Table 3).

Table 3: Univariate associations with momentary QoL

| | Univariate Model | | | |
	B	CI min	CI max	P-value
Comprehensive QoL	.17	.11	.23	<.001
Session, linear	.05	-.01	.11	.123
Age	-.06	-.12	.01	.081
Gender, women	.01	-.05	.07	.723
Barthel Index	-.006	-.07	.06	.859
GDS score	-.16	-.22	-.10	<.001
FAST score	.04	-.03	.10	.240
Random effects				
AR diagonal	.90	.84	.96	<.001
AR rho	.39	.35	.43	<.001
Variance between facilities	.08	.03	.22	.062

Note. B= z-standardized B coefficient that can be interpreted as standardized beta coefficient, 95% CI = lower and upper limit 95% Confidence interval, P-value= level of significance, AR diagonal= random variance of session of measurements between individuals, AR rho= residual correlation between sessions of measurement, QoL=quality of life, GDS= Geriatric Depression Scale, FAST= Functional Assessment Staging. N=148 across models (two cases could not be imputed) *Table 3 is based on Table 2 in the article published by Junge et al. (2020)(1)

3.4 Multiple Associations

Momentary QoL was not significantly related to session of measurement (B=.03, CI=-.02/.09, *p*<.264); FAST (B=.04, CI =-.04/.13, *p*<.358); gender (B=.03 CI=-.03/.09, *p*<.321); Barthel Index (B=-.02, CI =-.11/.06, *p*<.602) and age (B =-.06, CI=-.13/.00, *p*=.054); in our multiple model (Table 4). At baseline momentary QoL was significantly negatively related to GDS (B=-.13, CI =-.19/-.06, *p*<.001) and significantly positively related to comprehensive measured QoL (B=.14, CI=.08/.20, *p*<.001). Regarding the random effects in our multiple model, the correlation between two sessions of measuring QoL was significant as well with *B* = .37 (CI .33/.41, *p* < .001; Table 4). The random variance between facilities was not significant in the multiple model as well. (B=.09, CI=-.03/.25, *p*=.058)

Furthermore we found that QUALIDEM subscales: 'positive affect' (B=.17, CI =.11/.23, p<.001) and 'negative affect' (B=.13, CI =.07/.19, p<.001), 'social relationships' (B=.16, CI =.09/.22, p<.001); 'social isolation' (B=.07, CI =.01/.14, p=.27) and 'restlessness' (B=.07, CI =.01/.14, p=.23) were significantly related to comprehensive QoL (Table 5).

Table 4: Multiple associations with momentary QoL

	Multiple Model			
	B	CI min	CI max	P-value
Comprehensive QoL	.14	.08	.20	<.001
Session, linear	.03	-.02	.09	.264
Age	-.06	-.13	.00	.054
Gender, women	.03	-.03	.09	.321
Barthel Index	-.02	-.11	.06	.602
GDS score	-.13	-.19	-.06	<.001
FAST score	.04	-.04	.13	.358
Random effects				
AR diagonal	.88	.82	.95	<.001
AR rho	.37	.33	.41	<.001
Variance between facilities	.09	.03	.25	.058

Note. B= z-standardized B coefficient that can be interpreted as standardized beta coefficient, 95% CI = lower and upper limit 95% Confidence interval, P-value= level of significance, AR diagonal= random variance of session of measurements between individuals, AR rho= residual correlation between sessions of measurement, QoL=quality of life, GDS= Geriatric Depression Scale, FAST= Functional Assessment Staging. N=148 across models (two cases could not be imputed) * Table 4 is based on Table 2 in the article published by Junge et al. (2020)(1)

Table 5: Multiple associations of momentary QoL with comprehensive QUALIDEM subscales

QUALIDEM subscale	B	CI min	CI max	P-value
Care relationship	.02	-.04	.08	.535
Positive affect	.17	.11	.23	<.001
Negative affect	.13	.07	.19	<.001
Restlessness	.07	.01	.14	.023
Positive self-image	-.01	-.07	.05	.836
Social relationships	.16	.09	.22	<.001
Social isolation	.07	.01	.14	.027
Feeling at home	.04	-.02	.11	.212
Having something to do	.03	-.04	.09	.441

Note. B= z-standardized B coefficient that can be interpreted as standardized beta coefficient. Coefficients of each subscale were derived from a separate model, which have been adjusted for age, gender, time, GDS, Barthel Index and FAST as described in the analysis section. N=148 across models (two cases could not be imputed)

*Table 5 is based on Table 3 in the article published by Junge et al. (2020) (1)

4 Discussion

4.1 Associations of QoL and the subscales of QUALIDEM

Regarding the main hypothesis, of how momentary and comprehensive QoL would be related to each other, we have shown a significant positive relation between the short eight-item version and long-item version of QUALIDEM.

Junge et al. (2020) showed the relation between momentary QoL and comprehensive QoL at different time points adjusting for covariates that are common in geriatrics such as FAST, GDS and Barthel Index to find associations in an univariate and multiple model.(1) Thus, relations between QoL, functional status, cognitive status and depressive symptoms had been shown in the investigated sample group of 150 PwD living in nursing homes. Regarding the findings of previous studies, we have confirmed that depressive symptoms were negatively related to QoL (40), which we showed in our univariate and multiple model.(1)

To complete our validation of our newly implemented eight-item version of QUALIDEM, the subscales of QUALIDEM had been analyzed in order to see how they were related to momentary QoL. As shown in Table 5 and Table 3 of the article by Junge et al. (2020), we confirmed that momentary QoL was significantly positively associated with the QUALIDEM subscales: 'positive' and 'negative affect', 'restlessness', and 'social relationships' and 'social isolation'(1), which is line with literature.(30, 33, 35, 41, 42)

Especially Beerens et al. (2016) showed in their MEDLO study that PwD living in nursing homes scored higher QoL assessed on an individual level when having a positive mood and being engaged in social interactions at a state level assessment of QoL. (43). The subscales 'positive' and 'negative affect', 'restlessness', and 'social relationships' showed the significant results. Those findings might be explained because in the eight-item version of QUALIDEM most items were represented by those subscales. Whereas subscales such as 'care relationship' and 'positive self-image' were not associated with momentary QoL. That might be understood as a correlation to the selection of the eight items from subscales that were not related with 'self-image' and 'care relationship' as Junge et al. (2020) have shown in Table 3 of their article.(1) Regarding the covariates of QoL such as age, gender, Barthel Index and FAST we did not find significant associations with QoL, but other studies partially did.(44)

The internal consistency was evaluated as excellent, as indicated by Cronbach's alpha.

The subscales 'positive self-image', 'having something to do' and 'care relationship' varied across time which needs to be further examined. Still it might explain the non-significant association of the subscales 'positive self-image', 'having something to do' and 'care relationship' with momentary and comprehensive Qol. Dichter et al. (2014) suggest that phenomenon might be explained because items of the subscales 'positive self-image', 'having something to do' and 'care relationship' cannot be assessed in people with severe dementia.

4.2 Implications for Research and Practice

Technology-based interventions may help to optimize the workflow of the nursing staff. Even if an app-based intervention may be time intensive while being implemented, it might save time according to findings of Mueller et al. (2017).(45) As we have used a short eight-item version of QUALIDEM which has been approved as a valid and reliable instrument to assess QoL in people with mild and severe symptoms of dementia living in nursing homes. We may save time and costs as well, which needs to be proven in future studies examining the time factor itself. We suggest a

generous application of the short eight-item version of QUALIDEM in future clinical settings and studies. It may be used as a standard examination and documentation tool to assess and diagnose dementia in people living in nursing homes.

Although further longitudinal studies are necessary to explore more factors that might be related to QoL over time besides the factors we already have taken into account. One of those factors may be GDS and its relationship to QoL over time. As depression is a disease which is strongly related to dementia which occurs in higher GDS scores in PwD compared to people without dementia.(46) As well FAST and Barthel Index might be assessed over time to see how it will vary over time. Using eight items of QUALIDEM still represent the subscales of the long 37-item version of QUALDEM, accordingly that might help to manage the daily routine and working procedures of the staff more efficiently, which may be compared in a future study.

As studies showed that mood of PwD was related to factors such as unfulfilled needs or environmental factors (43), further studies should examine the relationship between felt care-relationship and QoL. Additionally, raters mood might affect the assessment of QoL according Robertson et al. (2017). (47) More studies need to investigate that relationship between caregivers and care receivers in order to identify an intra-individual variability or intra-observer variability. Care quality and communication may be improved by the benefit of that knowledge. Not only in elderly people with dementia but in other geriatric patient groups as well to apply adequate instruments for different kinds of diseases.(48, 49) Having showed good reliability of the new short eight-item version of QUALIDEM we recommend the practice of it in nursing homes to assess QoL in PwD. None regarding which version of QUALIDEM will be used to assess QoL of PwD in nursing homes, we assume the benefit of data using tablet computers may increase communication between nursing staff and PwD and improve the quality of care as well. Comparing different devices in order to evaluate their usability might offer relevant information for a clinical setting. Further use of technology-based assessment of QoL of PwD living in nursing homes is therefore highly recommended.(50) Elderly people who are diagnosed with other diseases related to cognitive impairment also may benefit of the use of tablet computers to assess QoL.(48) Dixon et al. (2020) compared in their study the submission of non-medication patient occurrences comparing a custom-built Web-based system and a previously used pen and paper system itself. They found that the custom-built Web-based system had 80 % more submissions which were accomplished 80 % faster compared to the older pen and paper system.(51) That study gives hints that paperless documentation of data in a clinical setting may not just speed up documentation processes. As well it might reduce errors related to report data of patients.(51)

Dykstra et al. (2009) pointed out the myth of "going paperless" and found that most clinics still use paper as a documentation form. Future studies may examine on a broader scale that time saving aspect and improving of care and safety aspect in patients with or without dementia in a clinical setting using paperless systems to document patient related variables not only in short-form surveys but also in comprehensive long-item versions of surveys such as the 37-item version of QUALIDEM.(52) The clues we have found in our study research and in our PflegeTab study needs to be further examined and proven but promise a future with a broader use of electronic devices such as tablets and smartphones in a clinical setting.

4.3   Limitations

In our study we took a further look into between-facility effects of the ten nursing homes where the 150 PwD were examined. A limitation can be found in the intra-individual variability and intra-observer variability, which we examined with the test-retest reliability that can be found in the Supplementary Table S2 of the attached article by Junge et al. (2020).(1) It has not been identified weather the variability is caused by intra-individual variability or intra-observer variability. Future studies may research variability between observers in order to examine intra-observer effects. Using the eight-item version of the QUALIDEM may be considered as a limitation as well, because the subscales 'care relationship', 'feeling at home', 'social isolation' and 'having something to do' were not represented by our choice of the eight items.
Which, might explain the non-significant association of the subscales 'positive self-image', 'having something to do' and 'care relationship' with momentary and comprehensive Qol. As Previous researchers explained that because items of the subscales 'positive self-image', 'having something to do' and 'care relationship' might not be assessed in people with severe dementia. Thus further studies might use our method in order to compare various Qol measurement tools and examine how items of different measurement tools represent QoL and use a long and short version of its surveys.
 Nevertheless, the QUALIDEM subscale 'social isolation' was significantly associated with our momentary QoL as shown in Table 3 in Junge et al. (2020).(1) That association might be explained because the items: 'loneliness', 'communication', 'sadness' and 'sociability' may cover partially the subscale 'social isolation' as well, Whereas the manual of QUALIDEM does not point out that relationship of the items 'loneliness', 'communication', 'sadness' and 'sociability'.(20) Therefore, a deeper examination of the subscale 'social isolation' might help

to understand its importance better in order to maybe reconsider using less items and still represent the subscale social isolation in future studies. We did not have a look on the intra-observer variability in our test-retest section, which may be further examined in comparable studies, to show if there is a difference between proxies, who examine PwD living in nursing homes.(1)

4.4 Conclusion and future investigations

Momentary QoL was significantly associated with comprehensive QoL, thus we could validate our short-item version of QUALIDEM, showing a good internal consistency as well.

Undermining findings of previous studies we have conformed the significant association between QoL and depressive symptoms in PwD.(1) Regarding the subscales of QUALIDEM we have shown the significant relation between momentary QoL and 'positive' and 'negative affect', 'care relationship', 'restlessness' and 'social isolation'.

A further investigation of the subscales 'social isolation', 'feeling at home', having something to do', positive self-image' and 'care relationship' may be accomplished in future studies to investigate how their specific items are related to the subscales we investigated in our study.

Especially the use of tablet computers as assessment tool might be an interesting standard procedure in the daily living of care receivers and caregivers. A broader understanding of the structure of QoL over time in PwD may improve the quality of assessment by the nursing staff and QoL in PwD simultaneously. Whereas the short eight-item version of QUALIDEM nor tablet computers have been implemented in many nursing homes their use is still innovative as an assessment tool. Future studies may offer promising results reproducing our study with larger study group to undermine our findings using the short eight-item version of QUALIDEM. Considering that FAST and Barthel Index were not able to be measured at momentary level, future studies may develop a momentary assessment to take a further look on the functional status and the activities of daily living to assess time-lagged associations between FAST, Barthel Index and momentary QoL.

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Eidesstattliche Versicherung / Anteilserklärung

„Ich, Stefan Junge, versichere an Eides statt durch meine eigenhändige Unterschrift, dass ich die vorgelegte Dissertation mit dem Thema: „Longitudinale Messung der Lebensqualität bei Menschen mit Demenz in Pflegeheimen" [deutsch] bzw. „Longitudinal assessment of quality of life in people with dementia living in nursing homes" [englisch] selbstständig und ohne nicht offengelegte Hilfe Dritter verfasst und keine anderen als die angegebenen Quellen und Hilfsmittel genutzt habe.

Alle Stellen, die wörtlich oder dem Sinne nach auf Publikationen oder Vorträgen anderer Autoren beruhen, sind als solche in korrekter Zitierung kenntlich gemacht. Die Abschnitte zu Methodik (insbesondere praktische Arbeiten, Laborbestimmungen, statistische Aufarbeitung) und Resultaten (insbesondere Abbildungen, Graphiken und Tabellen werden von mir verantwortet.

Meine Anteile an etwaigen Publikationen zu dieser Dissertation entsprechen denen, die in der untenstehenden gemeinsamen Erklärung mit dem/der Betreuer/in, angegeben sind. Für sämtliche im Rahmen der Dissertation entstandenen Publikationen wurden die Richtlinien des ICMJE (International Committee of Medical Journal Editors; www.icmje.og) zur Autorenschaft eingehalten. Ich erkläre ferner, dass mir die Satzung der Charité – Universitätsmedizin Berlin zur Sicherung Guter Wissenschaftlicher Praxis bekannt ist und ich mich zur Einhaltung dieser Satzung verpflichte.

Die Bedeutung dieser eidesstattlichen Versicherung und die strafrechtlichen Folgen einer unwahren eidesstattlichen Versicherung (§156,161 des Strafgesetzbuches) sind mir bekannt und bewusst."

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Datum   Unterschrift

Stefan Junge hatte an folgender Publikation den im Folgenden beschriebenen Anteil:

Publikation:

Junge S, Gellert P, O'Sullivan JL, Moller S, Voigt-Antons JN, Kuhlmey A, et al. Quality of life in people with dementia living in nursing homes: validation of an eight-item version of the QUALIDEM for intensive longitudinal assessment. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2020.

Beitrag im Einzelnen:

- Entwicklung des Forschungsthemas, inklusive Forschungsfrage und Auswertungskonzept
- Recherche zum aktuellen Forschungsstand zur Erfassung der Lebensqualität bei Menschen mit Demenz, nichtpharmakologische Interventionen und technologiebasierte Intervention von Demenz, longitudinale Erfassung von Lebensqualität in longitudinalen Studien mit Mehrebenenmodellen (Mixed Models)
- Durchführung der deskriptiven Statistik zu den Probanden und Variablen mithilfe von SPSS 25 (daraus ist Tabelle 1: „sample characteristics" im Artikel Junge et al. hervorgegangen)
- Durchführung der univariaten und multivariaten Statistik der in situ stattfindenden und wiederholten Kurzmessungen der Lebensqualität (daraus ist Tabelle 1: „sample characteristics" und Tabelle 2: „Univariate and multiple associations with momentary quality of life" der Publikation hervorgegangen)
- Durchführung der multivariaten Statistik der in situ stattfindenden und wiederholten Kurzmessungen der Lebensqualität mit den Domänen (Subskalen) von QUALIDEM (daraus ist Tabelle 3: „Multiple associations of momentary quality of life with comprehensive QUALIDEM subscales" der Publikation hervorgegangen)
- Darstellung der durchschnittlichen in situ Lebensqualität zu unterschiedlichen Zeitpunkten und der der vorhergesagten in situ Lebensqualität zu unterschiedlichen Zeitpunkten (daraus ist Figur 1 der Publikation hervorgegangen)
- Auswertung der Ergebnisse
- Validierung der Ergebnisse mithilfe von der Internen Konsistenz

- Selbstständiges Verfassen des ersten Artikelentwurfes inklusive einer eingehenden Diskussion der Ergebnisse und dem Verfassen der deutsch- und englischsprachigen Abstracts. Überarbeitungsprozess im Austausch mit Paul Gellert und Julie Lorraine O'Sullivan

- Einarbeitung der Hinweise der Ko-Autor*innen in die finale Version

- Nach Ablehnung durch das Journal of International Geriatric Psychiatry erfolgte eine erneute Überarbeitung, Kürzung, mit Unterstützung durch Paul Gellert für QUALITY OF LIFE RESEARCH.

_____ Unterschrift Stefan Junge

Auszug aus der Journal Summary List

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3	VALUE IN HEALTH	7,497	5.494	0.017360
4	HEALTH AFFAIRS	15,756	4.843	0.055270
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6	JOURNAL OF MEDICAL INTERNET RESEARCH	10,875	4.671	0.027410
7	JMIR mHealth and uHealth	1,418	4.541	0.004630
8	HEALTH TECHNOLOGY ASSESSMENT	5,630	4.513	0.011340
9	MEDICAL EDUCATION	9,440	4.405	0.011900
10	Implementation Science	7,206	4.345	0.017810
11	JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION	8,713	4.270	0.017580
12	JOURNAL OF CLINICAL EPIDEMIOLOGY	24,063	4.245	0.027230
13	JOURNAL OF GENERAL INTERNAL MEDICINE	17,822	4.005	0.028500
14	PHARMACOECONOMICS	4,255	3.989	0.007290
15	PALLIATIVE MEDICINE	4,636	3.780	0.008580
16	MEDICAL CARE	18,853	3.338	0.022590
17	JOURNAL OF HEALTH ECONOMICS	6,509	3.250	0.013920
18	JOURNAL OF PAIN AND SYMPTOM MANAGEMENT	9,734	3.249	0.013980
19	JOURNAL OF TELEMEDICINE AND TELECARE	2,683	3.046	0.003930
20	MEDICAL DECISION MAKING	4,718	3.012	0.009230
	INTERNATIONAL JOURNAL OF MEDICAL			

21	INFORMATICS	4,584	2.957	0.006600
22	Journal of Patient Safety	785	2.683	0.002120
23	SUPPORTIVE CARE IN CANCER	10,484	2.676	0.024580
24	HEALTH SERVICES RESEARCH	6,994	2.667	0.014330
25	Patient-Patient Centered Outcomes Research	828	2.660	0.002620
26	INTERNATIONAL JOURNAL FOR QUALITY IN HEALTH CARE	4,172	2.554	0.004540
27	ADVANCES IN HEALTH SCIENCES EDUCATION	2,341	2.552	0.004820
28	BMC Medical Research Methodology	8,196	2.524	0.019280
29	JOURNAL OF PALLIATIVE MEDICINE	5,417	2.490	0.011670
30	Journal of Managed Care & Specialty Pharmacy	774	2.464	0.002760
31	MEDICAL TEACHER	6,836	2.450	0.010400
32	HEALTH POLICY AND PLANNING	4,553	2.420	0.009280
33	EUROPEAN JOURNAL OF CANCER CARE	2,576	2.409	0.004330
34	QUALITY OF LIFE RESEARCH	11,646	2.392	0.018940
35	BMJ Supportive & Palliative Care	774	2.385	0.002870
36	Simulation in Healthcare-Journal of the Society for Simulation in Healthcare	1,210	2.340	0.002320
37	BMC Palliative Care	976	2.335	0.003090
38	HEALTH ECONOMICS	5,672	2.319	0.010080
39	MEDICAL CARE RESEARCH AND REVIEW	2,201	2.315	0.004290
40	HEALTH POLICY	6,450	2.293	0.010130
41	STATISTICAL METHODS IN MEDICAL RESEARCH	3,435	2.284	0.009480
42	Health and Quality of Life Outcomes	7,058	2.278	0.011190
43	JOURNAL OF MEDICAL ECONOMICS	1,814	2.264	0.005720
44	HEALTH EXPECTATIONS	2,524	2.173	0.005370

45	Telemedicine and e-Health	3,028	2.165	0.006850
46	JOURNAL OF MEDICAL SYSTEMS	3,751	2.098	0.006730
47	Current Opinion in Supportive and Palliative Care	939	2.073	0.002620
48	Therapeutics and Clinical Risk Management	2,357	1.995	0.004150
49	JOURNAL OF SCHOOL HEALTH	3,404	1.935	0.004180
50	Journal of Comparative Effectiveness Research	446	1.906	0.002130
51	Applied Health Economics and Health Policy	900	1.885	0.002740
52	Disability and Health Journal	979	1.863	0.002890

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Quality of life in people with dementia living in nursing homes: validation of an eight-item version of the QUALIDEM for intensive longitudinal assessment

Stefan Junge[1] · Paul Gellert[1] · Julie Lorraine O'Sullivan[1] · Sebastian Möller[2] · Jan-Niklas Voigt-Antons[2] · Adelheid Kuhlmey[1] · Johanna Nordheim[1]

Abstract

Purpose Our aim was to examine whether quality of life which was repeatedly assessed over time is related with the comprehensive assessment of quality of life (QoL) and thereby to validate a brief QoL assessment.

Method This longitudinal study used a comprehensive assessment of quality of life at baseline (QUALIDEM; 37 items) to validate an eight-item version of QUALIDEM to assess momentary quality of life which was repeatedly administered using a tablet device after baseline. In all, 150 people with dementia from 10 long-term facilities participated. Momentary quality of life and comprehensive quality of life, age, gender, activities of daily living (Barthel Index), Functional assessment staging (FAST), and Geriatric Depression (GDS) have been assessed.

Results Comprehensive and momentary quality of life showed good internal consistency with Cronbach's alpha of .86 and .88 to .93, respectively. For multiple associations of momentary quality of life with the comprehensive quality of life, momentary quality of life was significantly related to comprehensive quality of life ($B = .14$, CI .08/.20) and GDS ($B = -.13$, CI $-.19/-.06$). More specifically, the comprehensive QUALIDEM subscales 'positive affect', 'negative affect', 'restlessness', and 'social relationships' showed significant positive associations with momentary quality of life ($p < .001$).

Conclusion We found that momentary quality of life, reliably assessed by tablet, was associated with comprehensive measures of quality of life and depressive symptoms in people with dementia. Broader use of tablet-based assessments within frequent QoL measurements may enhance time management of nursing staff and may improve the care quality and communication between staff and people with dementia.

Keywords Caregiving · Well-being · Nursing home · Quality of life · Alzheimer's disease · Touchscreen tablet

✉ Stefan Junge
stefan.junge@charite.de

1 Institute of Medical Sociology and Rehabilitation Science, Charité – Universitätsmedizin, Charitéplatz 1, 10117 Berlin, Germany

2 Quality and Usability Lab, Technical University of Berlin, Ernst-Reuter-Platz 7, 10587 Berlin, Germany

Introduction

As there is not yet a curative treatment for dementia, a major goal of caring for people with dementia (PwD) is the maintenance of quality of life (QoL). In the USA [1, 2] as well as in Germany [3], about half of the older adults aged 65 and more living in nursing homes are diagnosed with dementia, which is 19-fold higher than the prevalence of dementia in individuals over 65 living in the community [3].

Even though there is a consensus about the importance of QoL as a goal of care in PwD, there is still a debate about theory, assessment, and factors associated with QoL in PwD [4]. However, so far only a few assessment tools are based on theory; most were proxy rating compared to self-rating and conceptualized QoL as general health related or domain specific [5]. Therefore, reliable instruments to assess QoL

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are necessary. In a recent systematic review of QoL in PwD, three factors that are positively associated with a better QoL were having close relationships, social engagement, and functional abilities. [6]. Focusing on the psychosocial domains of QoL in PwD, the QoL assessment tool QUALI-DEM showed the best acceptability interviewing PwD and their proxies. It was considered as acceptable in the long and short forms profiling PwD with mild-to-very severe stages of dementia living in nursing homes [4, 7–9].

Although many established QoL instruments allow a comprehensive assessment of QoL in PwD, momentary variations in QoL across time may be uncaptured [10]. Eco-logical Momentary Assessment (EMA) showed accuracy, minimization of retrospective bias, and revealing dynamic processes as compared to more traditional comprehensive QoL assessments across studies [11, 12]. Having a positive mood and being in social interaction assessed on a momen-tary level, i.e., assessed on a daily basis, has been related to a higher level of QoL. These findings were assessed on a comprehensive-level QoL (i.e., by the QoL-AD) in the Maastricht Electronic Daily Life Observation (MEDLO) study [13] as well as in other intervention studies in PwD [14]. These studies provided first hints about the association of momentary and comprehensive assessment of QoL.

New technologies may help to assess QoL in PwD due to the frequent QoL measurements across time. Previous stud-ies suggest the feasible use of technology-based and more specifically touchscreen-based assessments for elderly peo-ple, PwD, and other people with neurodegenerative disorders [15–17]. Other studies investigated the use of smartphones to measure the momentary QoL in PwD and people with cognitive impairment and identified a good acceptability, feasibility, and accuracy as well [18–21]. However, further research is needed that examines the relation of momentary QoL with comprehensively assessed QoL in PwD.

Aims of the study

The aim of our study was to validate a brief version of the QUALIDEM that would be suitable for momentary assess-ment by analyzing the association of momentary (assessed at several time points) and comprehensive QoL in PwD living in nursing homes. We investigated factors that were associ-ated in the eight-item and the 37-item version of QUALI-DEM at baseline measurements. Inspecting correlations of those two scales may help us to enhance our knowledge on the mechanisms of QoL over time and may be helpful for the nursing staff to assess QoL in the future. In the first step, we aimed at testing the momentary and time-lagged reli-ability of a momentary assessment of QoL. Furthermore, we hypothesized a positive association of momentary QoL with comprehensive QoL. Additionally, we hypothesized that the

relationship between momentary and comprehensive QoL exists when adjusting for age, gender, cognitive status, func-tional status, and depressive symptoms as well as temporal trend and between-facility variation.

Methods

Study design

The PflegeTab (*engl.* CareTab) study aimed to develop and evaluate a tablet-based psychosocial intervention tailored to the needs of PwD. A tablet application was developed and combined with innovative care concepts in order to enable a flexible, patient-centered care approach. The app was tested in ten nursing homes in Berlin over an 8-week intervention period, in which participating residents received activation sessions 3 times per week for up to 30 min. The full 37-item version of the QUALIDEM questionnaire was used for the assessment of comprehensive QoL before and after the intervention period. In the present analyses in this article, we only regarded the individual measurements that were administered before the intervention (at baseline). As our main focus lay on momentary and comprehensive QoL, momentary QoL was measured via tablet during the inter-vention period before and after each activation session (For the present analyses, before session assessments were used only; Table 1).

Participants and procedure

The planned sample size of the PflegeTab study was $N = 240$ PwD across eight nursing homes [22]. The sam-ple size calculation was based on the main study, which included a randomized trial design, where the sample size referred to a medium-large effect size of Cohen's $d = 0.5$ ($\alpha = 0.05$; $1 - \beta = 0.80$; 20% dropout rate; between clus-ter variance ICC $= 0.005$; G*Power 3.1) between the two arms where we primarily used the assessments at baseline (see ISRCTN98947160). Although the number of par-ticipating care facilities was increased to ten during the planning phase, the target sample size could not be fully achieved. Participants were included if they were nursing home residents and had a medical diagnosis of dementia (International Statistical Classification of Diseases and Related Health Problems—ICD-10: F00-F03), including Alzheimer's disease, vascular dementia, and unspecified dementia [23]. Participants were excluded if other seri-ous chronic psychiatric diagnosis were given F10-29, exceptions: F10.1; F17.1; F17.2; F32.2; and F32.3 may be included. An admission to the nursing home less than 4 weeks beforehand was also a criterion for exclusion. A total of 203 people (eligible nursing home residents or

Table 1 Sample characteristics

Scale	Mean (SD)	Empirical range	Items	N	Cronbach's α
Age, years	84.9 (7.1)	53–100	1	150	–
Women, %	75		1	112	–
Depressive symptoms, GDS	3.9 (2.9)	0–15	15	111	.68
Functional status, Barthel Index/ADL	54.1 (26.3)	0–95	10	149	.89
Dementia stage, FAST	9.0 (1.9)	4–16	16	149	.75
Baseline momentary QoL	5.4 (1.2)	1.6–7.0	8	150	.89
Baseline comprehensive QoL (sum score)	83.3 (14.9)	43–115	37	149	.86
QUALIDEM subscales					
Care relationship	15.5 (4.6)	1–21	7	148	.84
Positive affect	13.1 (3.7)	1–18	6	148	.86
Negative affect	6.4 (2.2)	0–9	3	148	.77
Restlessness	5.6 (2.6)	0–9	3	149	.63
Positive self-image	6.9 (2.0)	1–9	3	148	.49
Social relationship	11.5 (3.8)	1–18	6	149	.74
Social isolation	6.8 (1.9)	1–9	3	149	.42
Feeling at home	9.1 (2.6)	2–12	4	143	.60
Having something to do	2.2 (1.6)	0–6	2	149	.20

SD standard deviation, *GDS* Geriatric Depression Scale; *FAST* functional assessment staging; *ADL* activity of daily living; *QoL* quality of life

their conservators) were contacted and 163 PwD took part in the PflegeTab study. For the current analyses, 13 of the participants could not be included because the baseline momentary QoL and momentary QoL could not be imputed. As QUALIDEM is a proxy-rated assessment tool, all participants were assessed by the nursing staff working in the nursing homes (Fig. 1).

Measures

Comprehensive QoL was assessed with a 37-item version of QUALIDEM suitable for PwD with mild-to-severe dementia using proxy rating [24]. Out of 40 existing items, Item 9: 'Does not want to eat', item 30: 'Likes to lie down in bed', and item 15: 'Enjoys meals' was not represented

Panel A Individual mean scores of momentary quality of life across sessions
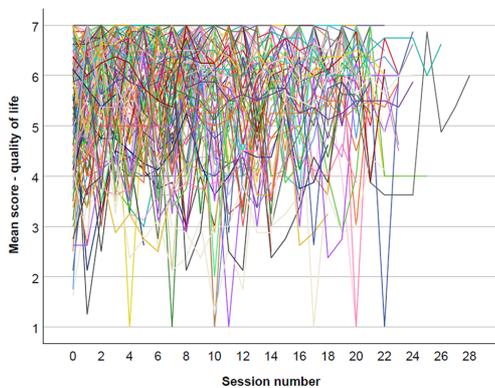
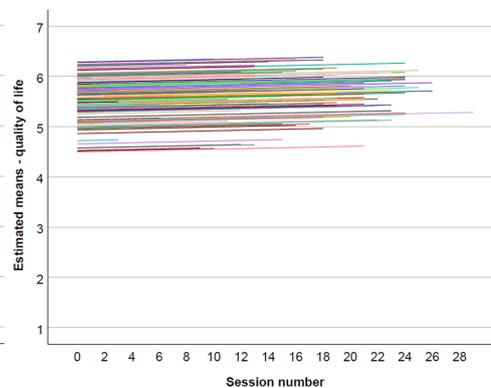**Panel B** Estimated individual mean scores of momentary quality of life across sessions

Fig. 1 **a** Displays the individual mean scores of momentary quality of life across sessions. **b** Shows the predicted individual mean scores of momentary quality of life across sessions estimated by a multivariate model with fixed effect (linear) of session number, random intercept, and slope

because we excluded the subscale J in our study; thus, 37 items remained. In order to test the main hypothesis, a sum score was created across all 37 items at baseline. Further, we studied the determinants of QoL according to the literature [25–27] to establish nine subscales: care relationship (7 items), positive affect (6 items), negative affect (3 items), restlessness (3 items), positive self-image (3 items), social relationship (6 items), social isolation (3 items), feeling at home (4 items), and having something to do (2 items) (Table). These subscales are sum scores across the respective items, which were presented in a Likert format ranging from never (0), rarely (1), and sometimes (2) to frequently (3). Across all 37 items, a principal component analyses (PCA) extracted ten components with an Eigenvalue over 1 although the visual evaluation of the Scree plot suggested four components only. The varimax-rotated PCA solution accounted for 67.2% of the overall variance. Next to the subscales, we created a composite sum score across all 37 items, which has been used extensively in the literature as well [25–30]. Thus, in our analyses, we look into both the comprehensive sum score (Table 2) as well as subscale results (Table 3) and its relation with momentary QoL.

Momentary QoL was assessed with an eight-item version from the 37-item long version of QUALIDEM. All eight items had been executed on tablet computers at repeated time points. Aiming to use a brief scale that was considered as suitable for the tablet-based momentary QoL assessment in real life nursing home environment by nurses, we chose eight items: restlessness [item 19 of the QUALIDEM], mood [item 10], anxiousness [item 6], body language [item 22], communication [item 12], happiness [item 05], sadness [item 11] and sociability [item 34] belonging to the four subscales: 'positive affect', 'negative affect', 'restlessness', and 'social

relationships' of the full 37-item version of QUALIDEM (i.e., subscale B, subscale C, subscale D, and subscale F) [8, 31]. As part of a workshop, the study team was selecting the items based on the following considerations: Two items from four subscales of the German QUALIDEM version were used for the short version. In addition, some scales were not suitable for nursing home residents with severe stages of dementia. The item length played a minor role and was relevant only when selecting the two items from a scale. In that case, shorter items were preferred, since we assumed that all items belonging to the same scale were assumed equivalent in content and therefore largely interchangeable.

Table 3 Multiple associations of momentary quality of life with comprehensive QUALIDEM subscales

QUALIDEM subscale	B	95%CI		P-value
Care relationship	.02	− .04	.08	.535
Positive affect	**.17**	**.11**	**.23**	**< .001**
Negative affect	**.13**	**.07**	**.19**	**< .001**
Restlessness	**.07**	**.01**	**.14**	**.023**
Positive self-image	− .01	− .07	.05	.836
Social relationships	**.16**	**.09**	**.22**	**< .001**
Social isolation	**.07**	**.01**	**.14**	**.027**
Feeling at home	.04	− .02	.11	.212
Having something to do	.03	− .04	.09	.441

B z-standardized B coefficient that can be interpreted as standardized beta coefficient. *P*-value level of significance (Significant values are shown in bold). Coefficients of each subscale were derived from a separate model, which have been adjusted for age, gender, time, GDS, Barthel Index, and FAST as described in the analysis section. *N* = 148 across models (two cases could not be imputed)

Table 2 Univariate and multiple associations with momentary quality of life

	Univariate model				Multiple model			
	B	95% CI		P-value	B	95% CI		P-value
Comprehensive QoL	**.17**	**.11**	**.23**	**< .001**	**.14**	**.08**	**.20**	**< .001**
Session, linear	.05	− .01	.11	.123	.03	− .02	.09	.264
Age	− .06	− .12	.01	.081	− .06	− .13	.00	.054
Gender, women	.01	− .05	.07	.723	.03	− .03	.09	.321
Barthel Index	− .006	− .07	.06	.859	− .02	− .11	.06	.602
GDS score	**− .16**	**− .22**	**− .10**	**< .001**	**− .13**	**− .19**	**− .06**	**< .001**
FAST score	.04	− .03	.10	.240	.04	− .04	.13	.358
Random effects								
AR diagonal	**.90**	**.84**	**.96**	**< .001**	**.88**	**.82**	**.95**	**< .001**
AR rho	**.39**	**.35**	**.43**	**< .001**	**.37**	**.33**	**.41**	**< .001**
Variance between facilities	.08	.03	.22	.062	.09	.03	.25	.058

B z-standardized B coefficient that can be interpreted as standardized beta coefficient, *95% CI* lower and upper limit 95% confidence interval, *P*-value level of significance (Significant values are shown in bold), *AR diagonal* random variance of session of measurements between individuals, *AR rho* residual correlation between sessions of measurement, *QoL* quality of life, *GDS* Geriatric Depression Scale, *FAST* Functional assessment staging. *N* = 148 across models (two cases could not be imputed)

Dementia stage was measured with the Functional assessment staging (FAST) which is scored from 1 to 16 for 7 consecutive stages and 9 substages [32]. As PwD progress in severity, the numerical value of the FAST increased, with stage 4 corresponding to mild dementia, stage 5 to moderate, stage 6 to moderately severe, and stage 7 to severe dementia. According to Arons et al. (2017), the QUALIDEM is applicable in PwD with all stages of dementia severity [7].

Functional status was measured with the Barthel Index [33]. Barthel Index is scored from 0 to 100, served as a covariate and activities of daily living (ADL) related to self-care activities such as bathing, dressing, grooming, and other activities. Barthel Index ranged from 0 to 95.

Depressive symptoms were measured with GDS-SF-15 (Geriatric Depression Scale– 15 items Short Form which served as a covariate [34]. Total score ranged from 0–15. A score of 5 or more indicated probable depression. GDS ranged from 0 to 15 points.

Session (time trend) refers to the measurement session where the eight-item QUALIDEM was administered. Session variable started from 0 (at baseline; first session, 1, 2, 3,…). Mostly, there were three sessions a week and the median total number of sessions per resident was 8 sessions. Using the session variable, the timing of the momentary assessment can be modeled.

Additional covariates were *ID* (i.e., unique identifier of facility), *age*, and *gender* of the residents.

Statistical analysis

The univariate and multivariate associations of momentary and comprehensive QoL were estimated using mixed modeling which takes the nested data structure of measurement occasions in individuals in nursing homes into account. Momentary QoL (level-1) was regressed on momentary session (time trend; level-1) and comprehensive variables, i.e., comprehensive QoL, age, gender, functional and cognitive status, and depressive symptoms (all level-2). The ID of the nursing home of each person with dementia was used as a clustering variable (level-3). Intercepts were allowed to vary across individuals and facilities (intercept only model; variance components). Furthermore, an autoregressive covariance matrix was assumed for the time variables to account for autocorrelation (based on inspection of fit indices [AIC; Akaike's Information Criterion [35], where smaller values indicate better fit: $\text{AIC}_{\text{autoregressive}} = 6272$; $\text{AIC}_{\text{unstructured}} = 6544$, without reaching convergence; $\text{AIC}_{\text{identity}} = 6617$; $\text{AIC}_{\text{variance components}} = 6622$] and theoretical plausibility). Prior to the estimation of the multivariate models, we inspected the trends graphically as well as compared the AIC values. Based on the inspection, we decided for a fixed slope random intercept model (AIC = 6272) as quadratic and cubic fixed and random effects did not

provide improvement in the fit of the model with the data (AIC = 6278 to 6307). All variables have been standardized allowing the coefficients to vary between − 1 and 1 and, thus, can be interpreted as beta coefficients. All data analyses were conducted with MIXED procedures in SPSS (IBM SPSS Statistics for Windows, Version 25.0, released 2017. Armonk, NY: IBM Corp.) using the Restricted Maximum Likelihood estimator (REML), which accommodates for unbalanced datasets, i.e., missing cases in repeated measure designs [35]. Scale missing values were imputed using Expectation–Maximization algorithm for Barthel Index ($n = 1$), FAST ($n = 1$), GDS ($n = 38$), and comprehensive QoL ($n = 1$). Models with and without imputation did not differ in the direction or magnitude of the main findings.

For the evaluation of the internal consistency, at each session (time point), Cronbach's alpha was used (Kuder-Richardson Reliability Coefficients KR20 in the case of binary items). Internal consistency was considered as excellent if Cronbach's alpha was $\alpha \geq .90$ or higher, as good if $\alpha \geq .80$, as acceptable if $\alpha \geq .70$ and as questionable to unacceptable if $\alpha \geq .60$ [36]. For test–retest reliability, lagged momentary QoL variables (lag 1, lag 2) were calculated and regressed on momentary QoL in a model that accounted for the nested structure as described above (except for using a variance components covariance structure to capture autocorrelation merely within the coefficients). According to Dichter et al. (2011), test–retest reliability can be seen as the response stability over time, which was operationalized as the regression coefficient of the same test across subsequent time points [37, 38]. Thereby, lag 1 refers to the regression of the value of momentary QoL in one session onto the value of momentary QoL in the prior session. Accordingly, lag 2 refers to the regression of the value of momentary QoL in one session onto the value assessed two sessions before. In the tested models, momentary QoL was compared with each lagged momentary QoL for the nested data structure (Supplementary Table S2).

Results

The sample compromised of 150 PwD from 10 long-term facilities with a mean age of 84.9 (SD 7.1) years (Table 1). The majority (75%; $n = 112$) were women. Mean GDS score was 3.9 (SD 2.9) and the mean Barthel Index score was 54.1 (SD 26.3). Concerning the dementia stage, the mean FAST score was 9.0 (SD = 1.9) at baseline, which indicates mild cognitive impairment. The mean Comprehensive QoL was 83.3 (SD 14.9), whereas the mean momentary QoL at baseline was 5.4 (SD 1.2). Ranging from 1 to 29 measurement

sessions the mean number of sessions (time trend) was 8.6 (SD 6.3).

Internal consistency

We found that the internal consistency of the comprehensive sum scale of the QUALIDEM was good with a Cronbach's alpha of $\alpha = .86$. Likewise, the internal consistency of the eight-item momentary QoL was excellent as indicated by Cronbach's alpha with a range from $\alpha = .88$ to $\alpha = .93$, indicating decent reliability at each time point (Supplementary Table S1). Regarding unidimensionality of the momentary QoL scale, a PCA extracted one factor with an Eigenvalue over 1 and the evaluation of the Scree plot suggested one factor as well. The PCA solution accounted for 62.6% (sums of squared loadings) of the overall variance. Regarding test–retest reliability, momentary QoL was associated with each lagged momentary QoL (i.e., lag 1) with $B = .40$ (CI .36/.44, $p < .001$) when accounting for the nested data structure (Supplementary Table S2). Additionally, the lagged association of momentary QoL lagged across two sessions of assessment (i.e., lag 2) was $B = .36$ (CI .31/.40, $p < .001$). Finally, in a model where both (consecutive lag 1 and lag 2 time points momentary QoL) were entered, lag 1 association was $B = .32$ (CI .27/.36, $p < .001$) and lag 2 was $B = .23$ (CI .19/.27, $p < .001$; Supplementary Table S2).

Univariate associations

Regarding univariate associations, momentary QoL was not significantly related to session of measurement ($B = .05$, CI $-.01/.11$, $p = .123$), age ($B = -.06$, CI $-.12/.1$, $p = .081$), gender ($B = .01$, CI $-.05/.07$, $p = .72$), Barthel Index ($B = -.006$, CI $-.07/.06$, $p = .86$), and FAST score ($B = .04$, CI $-.03/.10$, $p < .240$; Table 2). However, we did find a significant positive association of momentary QoL with comprehensive QoL ($B = .17$, CI .11/.23, $p < .001$) and a significant negative association of momentary QoL with GDS ($B = -.16$, CI $-.22/-.10$, $p < .001$).

Regarding the random effects in the univariate model, where momentary QoL was regressed on comprehensive QoL, the random variance of session of measurements between PwD (autoregression, diagonal) was significant in the univariate model ($B = .90$, CI .84/.96, $p < .001$), as well in the multiple model ($B = .90$, CI .82/.95, $p < .001$; Table 2). Furthermore, the residual correlation between two sessions of measurement was significant in the univariate model (autoregression, rho; $B = .39$, CI .35/.43, $p < .001$), as well as in the multiple model ($B = .37$, CI .33/.41, $p < .001$), indicating that a higher-than-average rating in one session is associated with a higher-than-average rating on the consecutive session. However, the random variance between

facilities was neither significant in the univariate model ($B = .08$, CI .03/.22, $p = .062$), nor in the multiple model ($B = .09$ CI .03/.25, $p = .058$).

Multiple associations

For the multiple associations of momentary QoL with the comprehensive QoL, momentary QoL was not significantly related to session of measurement ($B = .03$, CI $-.02/.09$, $p < .264$); Barthel Index ($B = -.02$, CI $-.11/.06$, $p < .602$); FAST ($B = .04$, CI $-.04/.13$, $p < .358$); age ($B = -.06$, CI $-.13/.00$, $p = .054$); and gender ($B = .03$ CI $-.03/.09$, $p < .321$). However, the momentary QoL was significantly positively related to comprehensive measured QoL at baseline ($B = .14$, CI .08/.20, $p < .001$) and significantly negatively related to GDS ($B = -.13$, CI $-.19/-.06$, $p < .001$).

Finally, concerning associations of QUALIDEM subscales with comprehensive QoL, positive ($B = .17$, CI .11/.23) and negative affect ($B = .13$, CI .07/.19), restlessness ($B = .07$, CI .01/.14) ,as well as social relationships ($B = .16$, CI .09/.22) and isolation ($B = .07$, CI .01/.14) were significantly related (all $p > .05$; see Table 3).

Discussion

Validating a short form of QUALIDEM for purposes of in the moment assessment of QoL and changes in QoL over time, we hypothesized a positive relation between momentary and comprehensive QoL with and without adjusting for covariates. While internal consistency of the momentary QoL was demonstrated, we found univariate and multiple associations of momentary and comprehensive QoL suggesting QoL can be assessed validly. In the multiple case, momentary QoL was significantly negatively related with GDS. Multiple associations of momentary QoL with comprehensive QUALIDEM subscales indicated positive and negative affect and restlessness, and social relationships and social isolation were significantly positively associated with momentary QoL, whereas the others were not.

In our multiple analysis, we found that GDS was substantially and negatively related with momentary QoL. This finding was in line with majority of the research that investigated mood, depressive symptoms, affective status, and happiness [39–41]. Further, most studies showed comparable results investigating multidimensional associations of the QUALIDEM subscales [25–30]. Moreover, in our study, we did not find significant outcomes regarding gender, age, FAST, and Barthel Index, which contradicts findings from the literature [42, 43]. Thus, more research is needed to examine the association of momentary QoL and other indicators of health and functioning.

Furthermore, we found subscales for positive and negative affect, restlessness, and social relationships that were significantly related with momentary QoL. This is largely in line with findings from the MEDLO study, showing that being in a positive mood and engaging in social interactions at state-level assessment was related to a higher QoL assessed on an individual level in PwD in nursing homes [13, 44]. Further studies showed that social engagement is essential for PwD and related with increased levels of QoL [40, 45]. Beerens et al. (2018) suggested focusing on the type of social interactions and rating the quality of interaction [44]. The subscales positive self-image, care relationship, and having something to do were not significantly associated with momentary and comprehensive QoL. This is in line with the literature because in people with very severe dementia the domains such as positive self-image, having something to do, and feeling at home cannot be assessed [46].

Nordheim et al. (2015) showed in their pilot study that the use of tablet computers by PwD living in nursing homes improved the contact to family members and the nursing staff. Additionally, the well-being of residents had been improved [47]. Additionally, technology may be assistive for PwD and can also be used as a telecare service in a home care setting. Furthermore, a combination of several technologies should be investigated regarding momentary and comprehensive QoL and other covariates (GDS, Barthel Index and FAST) of PwD living in nursing homes [48].

Dementia-specific assessment of QoL is multidimensional and depends on the individual environment of PwD. Adaption influences the rating of QoL of PwD living in nursing homes and are described in the adaptive coping model [31]. Ettema et al. (2007) described the life domains of QUALIDEM that were chosen by consensus [41]. Lawton et al. (1991) considered the well-being of elderly people as the main outcome which is affected by the person-environment system of PwD [49]. Due to this importance of variables that affect QoL, we took different variables into account. Momentary and comprehensive QoL were examined. Nursing home of every PwD had been used as a clustering variable to detect effects between the ten nursing homes. QoL instruments such as QUALIDEM had not yet been tested completely to investigate psychometrical variables.

Strengths and limitations

Strengths of our study include the ecological design with a large number of observations across time and an innovative and relevant research topic, which may inform future QoL assessment in research and practice. In our study, limitations include the moderate number of long-term care facilities

that may have covered the potential between-facility effects, which should be tested in future studies. Additionally, we were not able to measure other scales such as FAST or Barthel Index at momentary level; thus, time-lagged associations across scales at momentary level could not be detected in the present study design. Another limitation concerns the exclusion of important aspects of QoL, such as social isolation. The subscale 'social isolation' was represented in our sum score of the 37-item version of QUALIDEM with the item 16: 'Is rejected by other residents', item 20: 'Openly rejects contact with others', and item 32: 'Calls out'. Previous studies of reliability and validity between the 18-item version and the 37-item version of QUALIDEM showed that the subscales 'having something to do' and 'social isolation' were weakly or not scalable, according to the Loevingers coefficient of homogeneity and scalability [9, 38]. However, the subscale 'social isolation' was associated with our momentary QoL scale; thus, the short version may at least cover some aspects of social isolation. This might be due to the fact that communication, sociability, and sadness, which likely cover some aspects of social isolation and loneliness, were included in our short version. Nonetheless, future studies should inspect the further role of 'social isolation' and 'social relationships' in the eight-item version of QUALIDEM.

Implications for research and practice

Mobile technologies may help to monitor patients with mild and severe dementia or other clinical situations and can be a low-cost option to support caregivers of PwD in a non-clinical setting. Although intervention apps for PwD may be time intensive, it might save time, if the technology would be established and integrated in the activities of daily life [50]. Our eight-item Version QUALIDEM which represents the domains of QoL had been examined as a reliable and valid tool to assess QoL in people with mild and severe dementia living in nursing homes. It may be used by clinical staff in regular bases to assess and diagnose residents of nursing homes every day [51].

Nevertheless, more longitudinal studies are needed to determine if more factors are related to a change in QoL over time. This information could be important for the development of interventions that aim to improve QoL and for diagnosing and daily assessment of QoL of PwD living in nursing homes [13]. Other tools for the assessment of QoL may be compared and evaluated with our method as well. Furthermore, more touchscreen interventions should be conducted to compare those with our method and evaluate QoL including variables such as the QUALIDEM subscales. Moreover, studies using technology-based assessment tools

outline the advantages such as accuracy, efficiency, acceptability, and feasibility [18–21].

A positive association of momentary QoL and comprehensive QoL indicates that a touchscreen-based assessment instrument could be used to measure mood and social engagement of PwD [15].

According to other subscales such as positive self-image and care relationship, we found no association with momentary QoL, which is likely to be related to the selection of the eight state items from subscales that were not related with self-image and care relationship. However, both subscales were unlikely to vary substantially across short periods of time, which may be a further explanation for the non-significant relationship. Nonetheless, future studies should inspect the relationship between perceived care relationship and momentary QoL, being uncovered by our findings. Studies demonstrated that mood of PwD was correlated with factors such as unfulfilled needs or environmental factors [13]. Thus, investigating activity categories in future studies is needed.

The negative association of GDS and momentary QoL is important, as depression is a common comorbid disorder of dementia affecting between 23 and 54% of PwD, which is substantially higher compared to the general population [52, 53]. Thus further studies are necessary to find more relationships between the use of technology-based interventions and depression in PwD in nursing homes [17].

Robertson et al. showed that staff who were more distressed rated QoL of PwD lower than those raters being less distressed [54]. Further studies are necessary to find effects of raters on the variables that we are targeting for. Broader use of tablet-based assessments may improve the time management of nursing staff. This conclusion is in line with the study by Muller et al. that considered tablet-based assessment of dementia and mild cognitive disorders as an efficient assessment tool to diagnose dementia faster [55]. Using the short eight-item version of QUALIDEM for momentary assessment of QoL in our study showed good reliability; therefore, we suggest the broader implementation of the short eight-item version of QUALIDEM in further studies or clinical settings. The gain of data may improve the care quality and communication between staff and PwD. Future studies may investigate the use of tablet-based interventions in nursing home environments or other clinical settings, to evaluate QoL not only in PwD, but in other geriatric patient groups as well. In that case, disease-specific instruments should be applied [19, 51, 56, 57].

Conclusions

We found that momentary QoL was associated with comprehensive QoL as well as depressive symptoms in PwD living in nursing homes. The use of tablet-based assessments, especially the short eight-item version of QUALIDEM may enhance our knowledge on the mechanisms of QoL over time and may improve assessment by nursing staff and ultimately QoL in PwD.

Compliance with ethical standards

Conflict of interest All authors declare that there are no conflicts of interest.

Ethical approval This study was approved by the local ethics committee of the Charité (number EA1/013/16).

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Lebenslauf

Mein Lebenslauf wird aus datenrechtlichen Gründen in der elektronischen Version meiner Arbeit nicht veröffentlicht.

Publikationsliste

Danksagung