

RESEARCH ARTICLE

Discrepancies between self- and proxy-rated quality of life in people living with dementia

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Funding information

EuroQol Research Foundation, Grant/Award Number: 1582-RA

Abstract

INTRODUCTION: The aim of this study was to analyze discrepancies between self- and proxy-rated health-related quality of life (HRQoL), measured with the EuroQol 5 Dimension 5 Level survey (EQ-5D-5L), in people living with dementia (PlwD) and their caregivers on an individual response level.

METHODS: EQ-5D-5L, sociodemographic and clinical data were obtained from baseline data of $n = 174$ dyads of a cluster-randomized, controlled intervention trial. Self- and proxy-rated EQ-5D-5L health profiles were evaluated in terms of response distribution and agreement (weighted Kappa), and discrepancies in individual dimension level were analyzed using the Paretian Classification of Health Change (PCHC) as well as the presence and degree of inconsistencies between ratings.

RESULTS: PlwD had a mean age of 80.1, nearly the half were female and 82.3% were mildly to moderately cognitively impaired. PlwD reported a higher utility index than caregiver proxies (mean 0.75 vs. 0.68, 83% of PlwD > 0.5). According to the PCHC and inconsistency approach, 95% of PlwD rated their health differently compared to proxies; 66% with divergent responses in at least three EQ-5D-5L dimensions. Nine dyads (5%) showed identical ratings. Discrepancies of one higher or lower EQ-5D-5L response represented the most frequent discrepancy (35.4%). Caregivers were two times more likely to report “moderate problems,” representing the middle of the 5-point Likert scale. *Usual activities* had the lowest agreement between ratings (weighted kappa = 0.23). In PlwD reporting no or some problems in EQ-5D-5L-dimensions, proxies were more likely to report more problems and vice versa, especially in the more observable dimension *usual activities* and less likely in the less observable domains *pain/discomfort* and *anxiety/depression*.

DISCUSSION: The central tendency bias observed in proxy-ratings could be associated with assessment uncertainties, resulting in an underestimation (overestimation)

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in PlwD reporting better (worse) health. This diverging trend extends the knowledge from previous studies and underlines the need for more methodological research in this area.

KEYWORDS

dementia, discrepancies, health-related quality of life, proxy-perspective, patient-reported outcome measures

Highlights

- People living with dementia (PlwD) rate their health differently than proxies.
- Proxy-ratings over- or underestimate PlwD health when self-ratings are low or high.
- Proxies indicate a possible central tendency bias.
- Further research is needed to understand influencing factors.

1 | BACKGROUND

Globally estimated, there will be 152.8 million people living with dementia (PlwD) in 2050.¹ Most of them are cared for by a family-related informal caregiver, supported in their (instrumental) activities of daily living.

Health-related quality of life (HRQoL) has become a crucial parameter in dementia research, emphasizing the importance of valuing the preferred self-rated health perspective of PlwD.^{2,3} In addition to disease-related symptoms, knowledge about the PlwD HRQoL is essential to provide adequate dementia-related health services.⁴ The multidimensional HRQoL construct consists of functional, emotional, and social aspects, capturing the person's self-perception of their health state.⁵ For that, many generic and disease-specific instruments exist, aiming to measure treatment effectiveness in interventional studies and clinical trials. Preference-based HRQoL instruments are used in health economic evaluation studies and reimbursement decision-making procedures regarding the effectiveness of interventions.⁶ Their algorithms primarily based on preferences of the general public are used to generate health states in the respective group of people.³ Nevertheless, the disease progression of PlwD could affect the validity of self-ratings, resulting in an administration of proxy-ratings by informal caregivers using a proxy-person or proxy-proxy perspective.⁷ In the proxy-person perspective, the proxy is asked how he/she thinks the PlwD would rate his/her health if he/she was able to communicate. In the proxy-proxy perspective, the proxy rates the health of the PlwD from their own perspective.⁸

Studies have examined the agreement between self- and proxy-reports using the preference-based EuroQol 5 Dimension survey (EQ-5D) questionnaire, recommend by health technology assessment agencies (HTA) and used in dementia research.^{9–11} In its simplicity and shortness, the EQ-5D is a commonly used instrument in interventional and health economic studies, available and validated in different languages. In a form as an index value, generated based on its five health dimensions, the EQ-5D plays an essential role in

assessing economic evaluations, contributing to resource allocation in healthcare.¹²

EQ-5D proxy-ratings from informal caregivers do not always agree well with the PlwD responses. Proxies mainly report lower HRQoL than the PlwD.^{13–16} That discrepancy is likely associated with a higher caregiver burden, more functional limitations, and a higher cognitive decline in PlwD,^{16–19} causing weak rating agreements.^{14–16}

Although a large body of literature reports discrepancies between both rater types with higher PlwD self-ratings, agreements of the EQ-5D (indices and dimensions) refer to aggregated data.^{14–16} Information obtained from discrepancies based on individual responses between self- and proxy-ratings were not considered. Thus, using the EQ-5D-5L health profiles would be a promising approach to gather more evidence about the nature of these discrepancies.

To our knowledge, this is one of the first studies addressing a detailed examination of the individual response level to better understand discrepancies between self- and proxy-ratings.

2 | METHODS

2.1 | Study design and setting

We used baseline data from the InDePendent trial (ClinicalTrials.gov Identifier: NCT04741932), a cluster-randomized controlled intervention study in Germany, initiated in 2020 to evaluate an advanced model of collaborative care with extended nursing roles to improve the care and living situation of PlwD. Details of the study are published elsewhere.²⁰

2.2 | Sample

The respondents were dyads, consisting of community-dwelling PlwD and their informal caregivers. General practitioners or specialists (e.g.,

neurologists, psychiatrists) working in practitioner networks recruited PlwD and their informal caregivers. PlwD with an age ≥ 70 years, positively screened for dementia (DemTect screening score ≤ 8)²¹ or formally diagnosed with dementia were eligible to participate.

2.3 | Consent statement

All participants provided written informed consent (as approved by the ethical committees BB144/20; AS 81(bB)/2020; 2020-2081-zvBO).

2.4 | Data assessment and outcome measures

Clinical (e.g., cognitive functioning), health-related (e.g., HRQoL, depressive symptoms) and sociodemographic factors (e.g., age) were assessed via face to face interviews by dementia-specifically qualified nurses at PlwD and caregivers homes within one to three visits. The interview-assessments for PlwD and caregivers were carried out separately.²⁰

2.5 | HRQoL

The EQ-5D-5L consists of five dimensions (mobility, self-care, usual activity, pain, anxiety/depression) and a visual analogue scale (VAS), that asks to self-rate the person's today's health on a scale ranged from 0 (worst health) to 100 (best health).²² Mobility, self-care, and usual activity are categorized as the more and pain/discomfort and anxiety/depression as the less observable dimensions. With the five response options (1, "no problems"; 2, "slight problems"; 3, "moderate problems"; 4, "severe problems"; 5, "extreme problems") for each dimensions 5⁵ (3.125) unique health profiles can be described, ranging from "11111" (best) to "55555" (worst). Based on the given responses of the five dimensions, a single index score, anchored between 0 (for death) and 1 (perfect health), can be derived. The EQ-5D-5L was administered to PlwD (self-rating) and informal caregivers (proxy-proxy perspective). For calculating EQ-5D-5L indices, we used the German Time Trade-Off (TTO) value set by Ludwig et al.²³ TTO is a commonly used method to create preference-based value sets.²⁴ A value set is a collection of index scores for each specific EQ-5D health state.²⁵

2.6 | Sociodemographic data

Age, sex, marital status (married vs. not married), education (<10 years vs. >10 years of school), living situation (alone vs. not alone), and the relationship between PlwD and caregivers (spouse vs. non-spouse) were assessed to describe our sample.

RESEARCH IN CONTEXT

- 1. Systematic review:** The authors reviewed the literature on PubMed. Previous analyses comparing self- and proxy-ratings in people living with dementia (PlwD) typically reported agreement statistics, demonstrating that proxies underestimate PlwD health. Additional information from the individual response data concerning the discrepancies between the self- and proxy-responses across separate dimensions of the EuroQol 5 Dimension 5 Level survey (EQ-5D-5L) is lacking.
- 2. Interpretation:** Our findings indicate an over and underestimation of proxy-ratings when PlwD self-ratings were low or high, respectively. According to the individual-level health profile analysis, higher discrepancies in the more observable dimensions of "self-care" and "usual activities" of the EQ-5D-5L were observed, where proxies were up to two times more likely to select "moderate problem" responses, reflecting a possible central tendency bias.
- 3. Future directions:** The two trends of contrary response behavior (over- and underestimation) of both rater types underline the need for further methodological research, mainly to understand influencing factors.

2.7 | Individual and clinical measures

The caregiver burden was assessed by the 22-item Zarit Burden Interview (ZBI).²⁶ The individual score is calculated by summing all items (range 0 to 88), categorizing it into four groups: 0–20, "no to mild burden"; 21–40, "mild to moderate burden"; 41–60, "moderate to severe burden"; and ≥ 61 , "severe burden."²⁶

The Bayer Activities of Daily Living Scale (B-ADL) is a 25-item observer (completed by the informal caregivers) screening tool for dementia, capturing initial disease symptoms, ranging from daily living skills to cognitive impairments. The total score ranges from 1 (lowest possible impairment) to 10 (highest possible impairment).²⁷ The present long-term care grade was assessed to indicate how much care a PlwD needs. It is used by the German care insurance for long-term care and is categorized in five degrees (lowest to highest need of care).²⁸

The Mini-Mental State Examination (MMSE) is a widely used screening interview tool to grade the cognitive state in older people, consisting of cognitive tasks (e.g., memory, comprehension of direction, attention, reading, writing).²⁹ MMSE scores between "0" and "9" indicate a severe, "10" and "19" a moderate, and "20" and "25" a slight cognitive impairment.³⁰ It was administered by dementia-specifically qualified nurses.

For self-reported depressive symptoms of PlwD, the 15-item Geriatric Depression Scale (GDS) (short version) was used, capturing

characteristics of depression in affective and cognitive domains. Scores higher 5 indicate noticeable symptoms of depression.³¹

2.8 | Statistical analysis

Descriptive statistics were used to report the dyads' sociodemographic, health-related, and clinical characteristics, including correlation analyses of self- and proxy-ratings of the EQ-5D-5L (indices and dimensions) with MMSE, B-ADL, GDS, and ZBI.

We analyzed the response distribution of the EQ-5D-5L dimensions for self- and proxy-responses and calculated weighted Kappa coefficients to identify the degree of agreement. Cohens Kappa values <0.2 indicate a slight, 0.21–0.40 a fair, and >0.40 an acceptable agreement.³²

Subsequently, we conducted a three-stage EQ-5D health profile analysis on the individual level.

1. We used the Paretian Classification of Health Change (PCHC),³³ examining self- and proxy-discrepancies by creating four groups: (i) "Proxy better", proxy-rating is better on at least one EQ-5D-5L dimension and not worse on any other dimension compared to the self-rating; (ii) "Self better", proxy-rating is worse on at least one dimension and is not better on any other dimension; (iii) "same" no difference between self- and proxy-ratings; (iv) "mixed", differences in both directions (better or worse) between the ratings.
2. For inconsistencies between the raters in each EQ-5D-5L dimension, we used the method by Purba et al.,³⁴ assigning a score to each dyad category: 0 (identical responses between PlwD and caregiver across all dimensions) to 5 (different responses between PlwD and caregiver across all five dimensions). Based on the five-level response options (1–5) for each EQ-5D-5L dimension, distances ranged from "0" (identical reported responses) to "+4" when proxy reported "extreme problems" (5) and PlwD "no problems" and "–4" when proxy report "no problems" (1) and PlwD "extreme problems," respectively (5).
3. We categorized PlwD into (i) a group of PlwD reporting "no problems" (combining "no problems" and "slight problems") and (ii) a group of PlwD reporting "problems" (combining "moderate problems," "severe problems," and "extreme problems"), comparing discrepancies in these groups to assess whether an under- or overestimation exists from perfect health to worse health. For EQ-5D-5L indices, PlwD were categorized in three groups: Full health: >0.9; moderate health: 0.5–0.9; poor health: <0.5. Focusing on a person-centered view, we classified responses as positive if the caregiver (proxy) underestimated PlwD self-rating, and negative if the caregiver overestimated PlwD self-rating.

Subsequently, we conducted regression analyses to assess whether the distance between self- and proxy-ratings was associated with a higher or lower self-rating. Distances between the dimensions were ordered logistic regressed on the two grouped PlwD health states (no problems/problems), and distances in the index were linearly regressed

on the index groups (full, moderate or poor health) as a metric variable. Regressions were adjusted for sociodemographic variables, functional status (B-ADL, long-term care level), cognitive decline (MMSE), depressive symptoms (GDS), and caregiver burden (ZBI). Concerning the dependent variable, negative (positive) beta coefficients indicate an overestimation (underestimation) of proxy-ratings compared to the self-rating. Studies revealed that proxy-ratings depend on perceived caregiver burden,³⁵ increased impaired status,³⁵ limitations in cognitive functioning, and with higher depressive symptoms,^{36,37} which is why we adjusted for these variables (ZBI, B-ADL, MMSE, and GDS). There was no indication of multicollinearity as a confounding factor, as the correlation coefficients consistently remained below 0.5 between the variables.

For all analyses, the program "RStudio" and STATA 16 were used.

3 | RESULTS

3.1 | Descriptive analysis of the sample

In total, $n = 174$ dyads with complete EQ-5D-5L data were analyzed. In Table 1, characteristics of the dyads are described. Mean age of the PlwD was 80.1, 49.1% were female. The majority were living not alone (69.5%) and were mildly to moderately cognitively impaired (82.3%). Informal caregivers were younger (67.9 years old) and more likely female (67.8%).

The mean self-rated EQ-5D-5L index and EQ-VAS (index score: 0.75 ± 0.25 ; EQ-VAS: 61.03 ± 20.34) were higher than the proxy-ratings (index: 0.68 ± 0.23 ; EQ-VAS: 56.33 ± 18.72) with $n = 23$ PlwD and $n = 4$ proxy-ratings in perfect health (11111) and none in worst health state (55555). Most PlwD (83%) rated their own health higher than 0.5 using the index. PlwD, who lived alone, reported statistically significant higher self-rated health compared to PlwD, living together with their caregivers (EQ-5D index score 0.82 vs. 0.72). Only moderately cognitively impaired PlwD showed a statistically significant discrepancy in EQ-5D indices between self- and proxy-ratings (Table S1).

3.2 | Distribution of responses and dimensions agreement

Figure 1 depicts the distribution of responses. Proxies reported less often "no problems" and more often "moderate" to "extreme problems." Higher discrepancies occurred in more observable dimensions "self-care" and "usual activity" than in the less observable dimensions "anxiety/depression" and "pain/discomfort."

In Table 2, differences between the ratings across all five dimensions were depicted. Weighted kappa coefficients showed a fair agreement between ratings for "pain" (kappa = 0.398), "mobility" (kappa = 0.393), and "anxiety" (kappa = 0.367). The lowest kappa value (kappa = 0.228) has the dimension "usual activity."

There was a tendency for proxy-ratings to be lower (worse) when PlwD self-reported "no problems" across all five dimensions, and

TABLE 1 Characteristics of the dyads with full-EQ-5D-5L data ($n = 174$).

Parameter	PlWD	<i>n</i>	Informal caregiver
Sociodemographic variables			
Age (years), $M \pm SD$	80.1 ± 7.3	167	67.9 ± 12.4
Female sex, <i>n</i> (%)	84 (49.1)	171	116 (67)
Marital status, <i>n</i> (%)			
Married	113 (64.9)	174	
School education, <i>n</i> (%)		166	
≤ 10 years	101 (60.8)		
> 10 years	65 (39.2)		
Relationship to informal caregiver			
Type of relationship,		173	
Spouse <i>n</i> (%)	100 (57.8)		
Daughter/son, <i>n</i> (%)	64 (37.0)		
Living together, <i>n</i> (%)	121 (69.5)	174	
Clinical and functional status			
MMSE score, $M \pm SD$	19.2 ± 6.0	152	
0–9 (severe cognitively impaired), <i>n</i> (%)	15 (9.9)		
10–19 (moderate cognitively impaired), <i>n</i> (%)	69 (45.4)		
20–25 (slight cognitively impaired), <i>n</i> (%)	56 (36.8)		
26–30 (mild to no), <i>n</i> (%)	12 (7.9)		
GDS score, $M \pm SD$	3.53 ± 3.1	145	
Long-term care grade, <i>n</i> (%)		174	
No long-term care grade	49 (28.2)		
1	13 (7.5)		
2	36 (20.7)		
3	49 (28.2)		
4	24 (13.8)		
5	3 (1.7)		
B-ADL	6.5 ± 2.3	165	
Health-related Quality of Life of PlWD			
	Self-report		Proxy-report
EQ-5D-5L index, $M \pm SD$	0.75 ± 0.25	174	0.68 ± 0.23
0.9–1, <i>n</i> (%)	58 (33.3%)		26 (14.9%)
0.5–0.9, <i>n</i> (%)	87 (50.0%)		113 (64.9%)
< 0.5 , <i>n</i> (%)	29 (16.7)		35 (20.1%)
Living alone, $M \pm SD$	0.81 ± 0.19	53	0.71 ± 0.20
Living not alone, $M \pm SD$	0.72 ± 0.27	121	0.66 ± 0.24
EQ-5D-VAS, $M \pm SD$	61.03 ± 20.34	174	56.33 ± 18.72

Abbreviations: B-ADL, Bayer Activities of Daily Living Scale; EQ-5D-5L, EuroQol 5 Dimension 5 Level survey; GDS, Geriatric Depression Scale; *M*, mean; MMSE, Mini Mental Status Examination; *n*, number; PlWD, People living with dementia; *SD*, standard deviation; VAS, visual analogue scale.

higher (better) when PlWD self-reported “severe” or “extreme problems.” Proxies selected two times more often “moderate problems” (middle response option) compared to PlWD, especially in “usual activities” (self-rating: 12.6% vs. proxy-rating: 28.7%) with the highest discrepancy. Discrepancies were lowest in “pain/discomfort” and “anxiety/depression.”

3.3 | Health profile analysis on individual level and dimension-related distance level

According to the PCHC method, 48.3% of ratings were classified as “self-better”, 17.2% as “proxy-better”, and 5.2% as “same ratings”. The “same ratings” more often occurred when PlWD rated their own

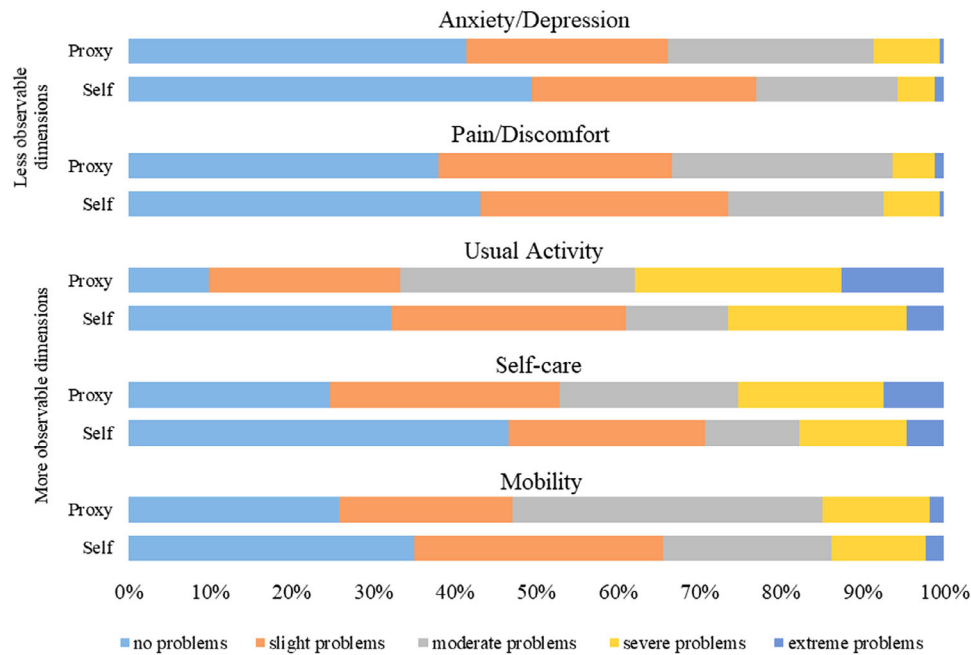


FIGURE 1 Distribution of responses to EuroQol 5 Dimension 5 Level (EQ-5D-5L) dimensions for self- and proxy-ratings.

health moderately (utility index 0.5 to 0.9), whereas “proxy better” and “self better” ratings occurred more frequently in lower (index <0.5) or higher (index >0.9) self-ratings, respectively. Following the inconsistency approach, the majority of the dyads (62.6%) gave different responses in at least three EQ-5D-5L dimensions (Table 3).

The most common response deviation was ± 1 (35.4%), and the lowest “ ± 4 ” (1.3%), occurring in “self-care” and “usual activity.” For the “self better” category, response deviations especially occurred in “usual activity” and “self-care” (Table 4).

By grouping the PlWD into “no problems” and “problems,” we again observed the following two trends: (i) when PlWD indicated “no problems,” caregivers reported higher problems; (ii) when PlWD indicated “problems,” caregivers reported less problems. These two trends were confirmed by our regression analyses (see Table S2 and Table S3) and particularly prevalent in the more observable dimensions “self-care,” “mobility,” and “usual activity.” The density plots of the health-profile discrepancies are demonstrated in Figure 2.

Considering the sample characteristics, PlWD reporting “poor health” (EQ-5D-5L index), had significantly more depressive symptoms (GDS scores: 1.9 in full, 4.0 in moderate, and 6.4 in poor health), slightly greater cognitive impairment (MMSE scores: 19.5, 19.2, and 18.5), more often a long-term care grade, and caused a higher caregiver burden (Zarit scores: 22.2, 23.2, 29.0). Further, GDS correlated strongest with the EQ-5D (index and dimensions) self-report (Table S4). Contrary, the proxy-rated B-ADL scores were highest in the self-rated “full-health” (6.8) and “poor-health” group (6.9), and lowest in the “moderate health” group (6.0), underlining different perceptions of both perspectives and the low correlation between B-ADL and EQ-5D self-report. According to the “moderate” and the “poor-health” groups, the EQ-5D index of the proxy-rating dropped less compared to the PlWD index. The trend of PlWD characteristics over self-rated health groups

(“no problems” vs. “problems”) was also seen across all five EQ-5D-5L dimensions (Table S5 and Table S6).

4 | DISCUSSION

We studied the extent of discrepancies between self- and proxy-rated HRQoL in PlWD and their informal caregivers based on individual EQ-5D-5L responses, revealing an opposing trend of proxy-ratings, underestimating (overestimating) PlWD health when PlWD self-rated their own health as “good” (“poor”). Proxies selected two times more frequently “moderate problems” than PlWD, representing a central tendency bias. Also, PlWD, primarily mildly to moderately cognitively impaired, self-reported their health aligned with the presence of depressive symptoms, supporting the validity of the EQ-5D-5L self-ratings.

Consistent with existing studies,³⁸ our findings show that proxy-ratings tend to underestimate self-rated HRQoL. Previous studies^{14–16} indicate that dyads show primarily weak to moderate agreements, worst in the “usual activity” and “self-care” dimensions. This aligns with our results, demonstrated by kappa coefficients indicating a fair agreement³² (kappa 0.2–0.4) across all EQ-5D-5L dimensions. Problems in self-care or usual activities could be associated with uncomfortable and embarrassing feelings, denied by PlWD, resulting in a biased reported state.¹³ On the other hand, caregivers may underestimate the PlWD abilities because their care focuses less on supporting the independence of the PlWD and is rather based on completing care tasks as efficiently as possible.¹⁸ In a qualitative study about the adequacy of long-term care provision, care recipients reported a feeling of overprotection and overprovision by their informal caregivers, assuming they do not fully understand what PlWD can do on their own.³⁹

TABLE 2 Distribution of EQ-5D-5L items responses for self and proxy, difference of self and proxy, and information of degree of agreement using weighted Kappa statistics, $n = 174$.

Parameter	EQ-5D-5L	Self n (%)	Proxy n (%)	Difference _{self-proxy}	p -Value	Weighted kappa	
More observable dimensions	<i>Mobility</i>				<0.001	0.393	
	No problems	61 (35.1)	45 (25.9)	16			
	Slight problems	53 (30.5)	37 (21.3)	16			
	Moderate problems	36 (20.7)	66 (37.9)	-30			
	Severe problems	20 (11.5)	23 (13.2)	-3			
	Extreme problems	4 (2.3)	3 (1.7)	1			
	Number of differences			66			
	<i>Self-care</i>					<0.001	0.342
	No problems	81 (46.6)	43 (24.7)	38			
	Slight problems	42 (24.1)	49 (28.2)	-7			
	Moderate problems	20 (11.5)	38 (21.8)	-18			
	Severe problems	23 (13.2)	31 (25.3)	-8			
	Extreme problems	8 (4.6)	13 (12.6)	-5			
	Number of differences			76			
	<i>Usual activity</i>					<0.001	0.228
No problems	56 (32.2)	17 (9.8)	39				
Slight problems	50 (28.7)	41 (23.6)	9				
Moderate problems	22 (12.6)	50 (28.7)	-28				
Severe problems	38 (21.8)	44 (25.3)	-6				
Extreme problems	8 (4.6)	22 (12.6)	-14				
Number of differences			96				
Less observable dimensions	<i>Pain/discomfort</i>				<0.001	0.398	
	No problems	75 (43.0)	66 (37.9)	9			
	Slight problems	53 (30.5)	50 (28.7)	3			
	Moderate problems	33 (19.0)	47 (27.0)	-14			
	Severe problems	12 (6.9)	9 (5.0)	3			
	Extreme problems	1 (0.6)	2 (1.1)	-1			
	Number of differences			30			
	<i>Anxiety/depression</i>					<0.001	0.367
	No problems	86 (49.4)	72 (41.3)	14			
	Slight problems	48 (27.6)	43 (24.7)	5			
Moderate problems	30 (17.2)	44 (25.3)	-14				
Severe problems	8 (4.6)	14 (8.0)	-6				
Extreme problems	2 (1.1)	1 (0.6)	1				
Number of differences			40				

Note: n : number; Self: reported by PlwD; Proxy: reported by the PlwDs informal caregivers. Abbreviations: EQ-5D-5L, EuroQol 5 Dimension 5 Level survey.

The different response behavior may also be caused by differences in the interpretation of the EQ-5D-5L's dimensions. Lay et al.⁴⁰ stated that older adults with and without cognitive impairments reported the most response issues of the EQ-5D-5L in usual activities and self-care, which may be interpreted as less appropriate in that sample. A further study concluded, that people consider their ability to do housework and leisure to be most closely related to usual activities,

which indicates a wide range of interpretation.⁴¹ Such differences in the understanding of the dimensions could also exist in the dementia context.

Considering the inconsistency³⁴ and PCHC method,³³ only $n = 9$ (5.3%) dyads had identical ratings, whereas the largest group (63%) had differences in at least three out of five EQ-5D-5L dimensions. Surprisingly and not in line with previous studies,¹⁷⁻¹⁹ the less observ-

TABLE 3 Discrepancies in health between self and proxy, according to the PCHC and the inconsistency.

Parameter	n	PCHC				Inconsistency						
		Same	Proxy better	Self better	Mixed	Categories						
		0	1	2	3	4	5					
Total, n (%)	174	9 (5.2)	30 (17.2)	84 (48.3)	51 (29.3)	9 (5.2)	24 (23.8)	32 (18.4)	58 (33.3)	31 (17.8)	20 (11.5)	
Groups EQ-5D-5L indices												
0.9–1, n (%)	58	1 (1.7)	0 (0)	44 (75.9)	13 (22.4)	1 (1.7)	6 (10.3)	17 (29.3)	16 (27.6)	14 (24.1)	4 (6.9)	
0.5–0.9, n (%)	87	6 (6.9)	23 (26.4)	36 (41.4)	22 (25.3)	6 (6.9)	14 (16.1)	11 (12.6)	31 (35.6)	13 (14.9)	12 (13.8)	
<0.5, n (%)	29	2 (6.9)	7 (24.1)	4 (13.8)	16 (55.2)	2 (6.9)	4 (13.8)	4 (13.8)	11 (37.9)	4 (13.8)	4 (13.8)	

Note: "Same": Identical PlwD and proxy-ratings; "Proxy better": Proxy-rating is better on at least one EQ-5D-5L dimension and not worse on any other dimension compared to the self-rating. "Self better": PlwD rating is better on at least one EQ-5D-5L dimension and not worse on any other dimension compared to the proxy-rating. "Mixed": response differences in both directions (better or worse) between self- and proxy-ratings; *Inconsistency*: A different response between self and proxy in a dimension, ranged from 0 (identical responses in all dimensions) to 5 (different responses in all five dimensions).²⁷

Abbreviations: EQ-5D-5L, EuroQol 5 Dimension 5 Level survey; PCHC, Paretian Classification of Health Change; PlwD, people living with dementia.

TABLE 4 Overview of distances between self- and proxy-ratings of EQ-5D-5L items, n (%).

Parameter	Distance	More observable dimensions			Less observable dimensions		Overall	
		Mobility	Self-care	Usual activity	Pain/discomfort	Anxiety/depression		
"Self worse"	–4	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	155 (17.8)
	–3	1 (0.6)	1 (0.6)	3 (1.7)	2 (1.1)	1 (1.1)	9 (1.0)	
	–2	5 (2.9)	8 (4.6)	8 (4.6)	5 (2.9)	4 (2.3)	30 (3.5)	
	–1	27 (15.5)	19 (10.9)	15 (8.6)	29 (16.7)	26 (14.9)	116 (13.3)	
	0	77 (44.3)	75 (43.1)	58 (33.3)	84 (48.3)	90 (51.7)	384 (44.2)	
"Self better"	1	41 (23.6)	32 (18.4)	45 (25.9)	43 (24.7)	31 (17.8)	192 (22.1)	331 (38.0)
	2	21 (12.1)	28 (16.1)	27 (15.5)	11 (6.3)	17 (9.8)	104 (12.0)	
	3	2 (1.1)	7 (4.0)	10 (5.7)	0 (0.0)	4 (2.3)	23 (2.6)	
	4	0 (0.0)	4 (2.3)	8 (4.6)	0 (0.0)	0 (0.0)	12 (1.3)	

Note: Distance: Discrepancy in proxy-responses, starting from proxy-proxy perspective with a range from –4 to 4; n of observations = 174; n of responses = 870 (174 × 5). In the focus of a person-centered view, we determine positive values as an underestimation and negative values as an overestimation of proxy-proxy perspective.

Abbreviation: EQ-5D-5L, EuroQol 5 Dimension 5 Level survey.

able dimensions (pain/discomfort, anxiety/depression) had the highest agreements. Most responses in these dimensions are distributed across the first three response levels (no, slight, and moderate problems) compared to the other three dimensions (mobility, self-care, usual activity), where all five response levels are used more frequently, leading to a higher potential of disagreement, especially prominent in higher self- and lower proxy-ratings (underestimation). Regarding the response distance approach of the five EQ-5D-5L dimensions, distances in the direction of an underestimation occurred more frequently than an overestimation with higher proportions in self-care and usual activity. Smith et al.⁴² developed a scoring algorithm to link self- and proxy-scores of a dementia-specific HRQoL instrument, estimating PlwD reports based on proxy-ratings. Considering that the most frequent distances are –1/1 in our sample, it is questionable which distance can be classified as acceptable to interpret proxy-ratings in the light of a person-centered view.

The individual health profile analysis revealed trends of a discordant response behavior. In PlwD, who rated themselves without or fewer problems, caregivers underestimate PlwD health, represented by more problems in the proxy-ratings. This trend was inverse in PlwD with a more deteriorated self-rating, where proxies indicated better health. Also, PlwD with a self-rated poor-health showed significantly higher depressive symptoms (GDS) and slight functional impairments (B-ADL), which is in line with the clinical picture of dementia.^{43,44} Interestingly, the self-reported GDS correlated most strongly with the PlwD health reports and the proxy-reported B-ADL with the caregiver reports of the EQ-5D, which the proxy-proxy perspective could explain. The caregiver responds based on her/his judgment, influenced by his/her expectations and/or assumptions.⁴⁵ Further, the raters could differ in their comprehension and interpretation of the questionnaire items, affecting the responses and supporting disagreements.^{40,41}

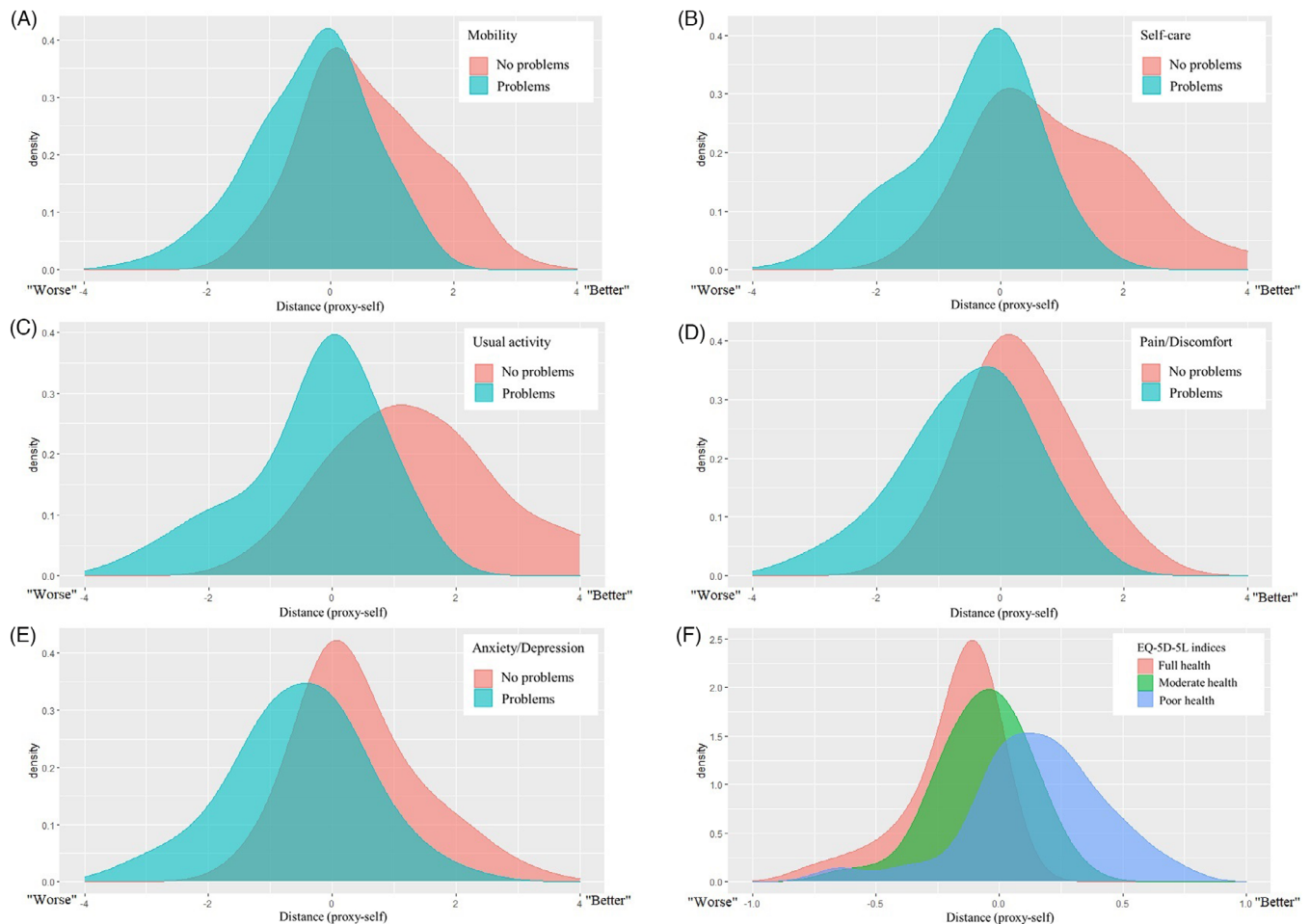


FIGURE 2 Density plots of EuroQol 5 Dimension 5 Level (EQ-5D-5L) dimensions and indices, grouped by severity of health. Note. “Worse”: Self-rating is worse than proxy-rating; “Better”: Self-rating is better than proxy-rating. Distance: Discrepancy in proxy-responses, starting from proxy-proxy perspective (proxy minus self) with a range from -4 to 4 . EQ-5D-5L Dimensions PlwD groups: (i) “no problems” (combining EQ-5D-5L response options “no problems” and “slight problems”) and (ii) “problems” (combining EQ-5D-5L response options “moderate problems,” “severe problems” and “extreme problems”) EQ-5D-5L indices PlwD groups: Full health >0.9 ; Moderate health indices 0.5 to 0.9 ; Poor health: <0.5 . PlwD, People living with dementia.

Finally, caregivers selected two times more often the mid-response “moderate problems” of the EQ-5D-5L. A mid-response option could strengthen the tendency toward the middle.^{46,47} An explanation could be the central tendency bias, defined as the trend to avoid a scale’s extremes and prefer responses closer to the middle of a scale,⁴⁸ resulting in a reduced interpretation of the data. To the authors’ knowledge, no research has addressed the central tendency bias in self- and proxy-ratings. A possible hypothesis might be that proxies are affected with uncertainty in the rating of PlwD health. This could be especially prevalent in caregivers living in a different household than the PlwD,³⁶ resulting in limited time to observe the PlwD situation. In our analysis, every third PlwD was living alone. Comparing PlwD living alone with PlwD living not alone, self- and proxy-rating discrepancies were significantly higher in PlwD living alone (0.810 ± 0.24 vs. 0.719 ± 0.22), and caregivers more often select “moderate problems” (32.2% vs. 14.1%). Additional research is needed to investigate these findings in more detail.

4.1 | Implications of the findings

When using proxy-data as a replacement for self-ratings, it might lead to a non-reimbursement of an effective treatment based on an HTA evaluation or a biased interpretation of findings in dementia-related interventional studies. Proxy-ratings should, therefore, be carefully interpreted³⁶ and not used as an unreflected self-rated substitute. A confident interpretation of proxy-ratings is crucial in making care-decisions for a PlwD,⁴⁹ avoiding over- and underprovision of care. A biased perception of the PlwD health could result in missed (overestimation) or unnecessary needs (underestimation). It would be interesting to monitor the trend of underestimated proxy-ratings in healthier individuals who progress into more severe disease stages where proxy-ratings tend to overestimate a person’s health. From a methodological perspective, examining if detected discrepancies are instrument-related and differ between generic and specific measures is highly relevant. Further, the extent to which a discrepancy leads

to a significant outcome might be discussed, especially concerning dementia-related interventions.

4.2 | Limitations

Our study is not free of limitations affecting the generalizability. First, the informal caregivers rated the PlwD health using a proxy-proxy perspective. The discrepancies and trends of under- and overestimation might be less pronounced between a proxy-person perspective and a self-rating. A comparative analysis of both proxy-perspectives (proxy-proxy vs. proxy-person) would be preferable in future research. A second limitation lies in the EQ-5D-5L measure. The instrument consists of a recall period of “today.” Although the self- and proxy-ratings were assessed simultaneously, dementia is a disease with common day-to-day health fluctuations. Therefore, PlwD and caregivers could refer to a different recall period than today, possibly affecting the ratings. The EQ-5D does not cover disease-specific nuances in PlwD, such as cognitive functioning or further disease-related dimensions. Thus, the response behavior of PlwD and their caregivers rely on the EQ-5D's five dimensions, which limits the discrepancies conclusions. The EQ-5D dimensions have a broad scope for interpretation.^{40,41} How PlwD and their caregivers understand and interpret these dimensions could be associated with discrepancies between self- and proxy-rated health. Comparable to other HRQoL measures, the EQ-5D is less responsive in health changes,⁵⁰ which biased interventional study conclusions. We, therefore, underpin the EQ-5D usage with critical reflection.

5 | CONCLUSION

Self- and proxy-rated health profiles were analyzed, extending the existing knowledge by demonstrating two contrasting trends of self- and proxy-response-behavior: proxies' underestimation of more healthy self-ratings and overestimation of less healthy self-ratings. This was accompanied by a two-times higher amount of proxies rating the health of PlwD with “moderate problems,” representing a central tendency bias, which rating uncertainties could cause, likely associated with not seeing PlwD frequently in their daily life routine. Conversely, more observable dimensions showed the highest discrepancies.

AUTHOR CONTRIBUTIONS

M.B.: Carried out the statistical data analyses, drafted the manuscript and is principal investigator of the funded project by the EuroQol Research Foundation; L.E.: Co-principal investigator of the funded project by the EuroQol Research Foundation, review of the manuscript; F.K.: Data preparation and data quality control, review of the manuscript; F.M.: Review of the manuscript; M.Pfaff.: Data analysis, review of the manuscript; M.Platen.: Review of the manuscript; A.R.: Review of the manuscript; N.W.: Review of the manuscript; A.S.: Review of the manuscript; N.v.d.B.: Evaluation concept of the InDePendent-trial, review of the manuscript; W.H.: Principal investigator of the

InDePendent-trial, review of the manuscript; B.M.: Co-principal investigator of the funded project by the EuroQol Research Foundation, contributed substantially to the final version of the manuscript. All authors have read and approved the final manuscript.

ACKNOWLEDGMENTS

We thank all participants for their participation in the InDePendent Study, and, thus, their contribution to this manuscript. The EuroQol Research Foundation funded this research (Grand No: 1582-RA). The funders have not influenced the conceptualization and conduct of the study and will not have any role in the data analysis and publication of the results. The authors' views do not necessarily reflect the views of the EuroQol group. The EuroQol Foundation is not involved in the study's design, data assessment, analyses, or interpretation of the results.

CONFLICT OF INTEREST STATEMENT

Dr Engel and PD Dr Bernhard Michalowsky are members of the EuroQol group. The authors declare that they have no competing interests. Author disclosures are available in the [supporting information](#).

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How to cite this article: Buchholz M, Engel L, Kleinke F, et al. Discrepancies between self- and proxy-rated quality of life in people living with dementia. *Alzheimer's Dement*. 2024;10:e12486. <https://doi.org/10.1002/trc2.12486>