Substituted judgement on quality of life in patients with dementia

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**ABSTRACT**

**Background:** Substituted judgement asks the proxy to decide what the patient would have decided, had he or she been competent. It’s unclear whether substituted judgement of the patient’s quality of life can serve as a surrogate measure in patients with dementia.

**Methods:** 212 patients with dementia and their proxies were interviewed in their homes. Dementia syndrome was characterized with cognitive, non-cognitive and functional scales. Quality of life (QoL) was assessed with the QoL-AD. **Results:** Substituted judgement of the patient’s QoL was unrelated to dementia severity but correlated with the proxy’s own QoL ($r = 0.356; p < 0.001$), also. Gender-specific analysis reveals that for male proxies the most important variable is severity of patient’s depression ($r = -0.895; p = 0.001; R^2 = 0.200$) while for female proxies it’s the proxy’s own QoL ($r = 0.371; p < 0.001; R^2 = 0.134$). Subjective burden correlates with the proxy’s QoL in females ($r = -0.282; p = 0.001$) but not in males ($r = -0.163, p = 0.161$). **Conclusion:** Substituted judgement of the patient’s QoL fails to pick up dementia severity. Substituted judgment is subject to proxy-related variables in a gender-dependent fashion and therefore not suited to serve as an appropriate surrogate of the patients’ quality of life.

**Key words:** Dementia; quality of life; QoL-AD; Alzheimer’s disease; caregiver
BACKGROUND

Alzheimer’s disease (AD) is a neurodegenerative disease with increasing prevalence in the aging societies of the Western hemisphere. With increasing therapeutic options for a multitude of diseases, a comparator is warranted to appraise efficacy of treatments across different diseases and to provide rational data for a fair allocation of resources of health care systems according to disease burden and therapeutic efficacy. One widely considered option to compare the impact of disease on patients’ life is to evaluate ‘Quality of life’ (QoL).

The World Health Organisation defines QoL as “the individual’s perceptions of their position in life in the context of the culture and value systems in which they live, and in relationship to their goals, expectations, and standards” (WHO-QoL, 1995). By this definition QoL is a subjective construct, being evaluated by the affected person by means of self reports. A widely used model assumes four domains to contribute to the individual’s QoL: behavioural competence, psychological well-being, objective environment, and self-perceived QoL [1].

Hence, it is widely accepted that QoL is a multidimensional construct containing both subjective and objective elements, such as perceived contentment and functional abilities, respectively. However, the validity of self-assessment of quality of life by dementia patients has been questioned [2-4].

Compared with their proxies, patients in early stages of dementia are likely to give overly optimistic ratings of their own mental capacities, lost functions, activities and social relationships [5]. Therefore clinicians and clinical investigators often rely on external evaluation of the patient by the caregiver and use this information as a substitute.

Substituted decision making for incompetent patients, however, is a much-discussed topic. Substituted judgement means that the substitute for the incompetent patient is the decision given by proxy considering what the patient would have decided, had he or she been competent [6]. However, agreement between the patient’s and the substitute’s decision in several studies was mediocre at best, and it was doubted whether substituted judgement is an adequate surrogate for the patient’s decisions [7,8]. Discussion between patient and
proxy was found to facilitate more accurate substituted judgment regarding the preferences of patients for life-sustaining therapies [8]. Overall, the accuracy of substituted judgements is subject to the kind of scenario to be decided, the amount of discussion between patient and surrogate and multiple clinically apparent patient- and proxy-related factors [9].

Dementia results in impaired cognition, language, insight, and judgement, and other behavioural and psychological symptoms of dementia (BPSD). Therefore, proxies often make decisions on the patient`s behalf. Proxies are even used as informants in clinical studies on therapeutic efficacy. This assumes that proxies describe the patient`s behaviour and well-being in an objective and reliable fashion. At least theoretically, the proxy should be able to know the preferences of the patient considering that dementia often extends over a long time giving proxy and patient plenty of time to discuss preferences. Empirically, however, proxy-rating of QoL in AD patients does not correlate well with the patients' own answers, challenging the validity of the reported answers by the caregiver [10-12].

In the present study in patients’ and proxies’ homes, the proxy was asked to rate the QoL of the patient as a substituted judgement, i.e. how the patient would assess his or her own QoL would he be competent.

METHODS

The study was performed according to institutional guidelines and the principles laid out in the Declaration of Helsinki. All patients and proxies gave their written consent to participate in this study.

Patients and Caregivers

The patients and their proxies were recruited from a cohort of patients interested in or applying for a short-term in-patient treatment at the Alzheimer Therapy Center Bad Aibling. Initial contact and screening of the eligibility to take part in the study were made via telephone by a study nurse. Criteria for inclusion in the study were a diagnosis of dementia of
mixed or Alzheimer's type performed by a general practitioner or neurologist/psychiatrist. Only patients living in one household with their primary proxy were included in the study. Baseline assessment was performed between September 2008 and June 2010 with a MMSE score of 3 and above.

Figure 1 near here

The remaining sample comprises 194 patients with either AD or mixed dementia (mean age 73.0 ± 7.1 years, range 52 – 89 years; 70.6 % male) and their proxies (mean age 69.0 ± 7.7 years, range 43 – 90 years; 27.8 % male). MMSE scores ranged from 3 - 28 (mean 17.3 ± 6.8).

All interviews took place in the domestic surroundings of the families after explaining the aim of the study and obtaining informed consent by both the patient and the proxy. Assessments were carried out by specially trained research assistants. Patients and proxies were interviewed separately to minimize bias and mutual influence on the responses.

Assessments

Mini-Mental Status Examination (MMSE [13]): The MMSE is the most commonly used instrument to stage the severity of dementia by assessing cognitive functions. It comprises tests on orientation, registration, short-term memory, language use, comprehension, and basic motor skills. Scores range from 0 - 30. Commonly, the scores on the Mini-Mental Status Examination are used to describe the severity of dementia. Patients are considered to be in mild stages of disease when scoring 20 points or above, to be in moderate stages of disease when scoring between 10 and 19, and severe when scoring 9 or less.

Behavioural pathology in Alzheimer's Disease Rating Scale (Behave-AD [14]): The Behave-AD is a clinical rating instrument to characterize the phenomenology of behavioural symptoms. It comprises 25 items, all of which are answered by the proxy.
**Geriatric Depression Scale (GDS [15]):** The Geriatric Depression scale uses a 15-item questionnaire to assess symptoms of depression and has been validated in cognitively intact and demented elderly [16,17].

**Activities of Daily living (Bayer–ADL [18]):** This scale is used to assess the deficits in the performance of the patients’ everyday activities. It comprises 25 items, all of which are answered by the proxy. Ratings are made on a 10-point Likert-type scale.

**Instrumental Activities of Daily living (iADL [19]):** This scale is used to assess the deficits in the performance of the patients’ everyday activities. It comprises 25 items, all of which are answered by the proxy. Ratings are made on a 10-point Likert-type scale.

**Euro-QoL (EQ-5D [20]):** The EQ-5D questionnaire is a generic instrument to measure health related QoL in five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It can be applied to patients as well as used in proxies to rate their own and the patients’ QoL [21,22]. There are two core components of this instrument: a description of the respondents own health in the above mentioned five domains (rated on a three point Likert scale each) and a rating of the overall own health on a visual analog scale (VAS, score 0 - 100). In order to capture the cognitive deterioration, a cognitive dimension was added (EQ-5D+C).

**Quality of Life in Alzheimer’s disease (QoL-AD)[23]:** The QOL-AD is a 13-item questionnaire on Quality of life and can be used both in patients with dementia [24] and healthy elderly controls [25]. The questionnaire covers the following domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. The QoL-AD is structured in a four-choice format, ranging from 1 being poor and 4 being excellent and refer to the patient’s current QOL. Possible scores range from 13-52 with higher scores indicating better QoL. In this study we administered the scale to the caregiver.
to measure their own QoL as well as the patients’ QoL via substituted judgment. A substituted judgment asks the caregiver to rate how they think the patient views his or her own QoL.

Data Analysis

All statistical analyses for the investigation of group differences were carried out using the statistics program SPSS (SPSS 15.0 for Windows, Chicago, Ill., 2001).

RESULTS

Quality of life – the caregiver’s self-assessment

Not surprisingly, less behavioural symptoms of the patients are associated with higher scores in the QoL-AD scale of the proxies (Behave-AD: $r = -0.278; p < 0.001$). Moreover, the QoL-AD score of the proxy is correlated with his self-assessed mood (GDS proxy-self: $r = -0.635; p < 0.001$) and his self-reported overall health (EQ-5d VAS: $r = 0.459; p < 0.001$).

To get further insight into the caregiver’s variables we performed a gender-specific analysis. Severity of the patient’s dementia was alike for male and female caregivers (MMSE $17.37 \pm 6.56$ and $17.10 \pm 6.89$, respectively, $p = 0.800$). Gender-specific analysis reveals that mood and overall health correlate with the QoL-AD score in both, male and female caregivers (GDS: males: $r = -0.528$, $p < 0.001$; females: $r = -0.646$, $p < 0.001$ and EQ-5d VAS: males: $r = 0.288$, $p = 0.035$; females: $r = 0.471$, $p < 0.001$). Despite the overall association of mood with QoL in both males and females the depressivity itself is gender-dependent (GDS: males: $2.66 \pm 2.60$, females: $3.91 \pm 2.84$, $p = 0.005$). Subjective QoL of the caregiver is associated with functional assessment of the patient by the caregiver, but only in female caregivers (females: $r = -0.241$, $p = 0.004$; males: $r = -0.157$, $p = 0.258$). The burden experienced by the proxy was slightly higher in females than in males ($2.14 \pm 0.87$ vs. $1.81 \pm 1.03$, respectively, $p = 0.046$). The burden correlates with the proxy’s QoL in females ($r = -0.282; p = 0.001$) but not in males ($r = -0.163$, $p = 0.161$).
Quality of life – substituted judgement

The proxy was asked to rate the QoL of the patient as a substituted judgement, i.e. how the patient would assess his or her own QoL would he be competent. Commonly, severity of dementia is staged according to the score in the MMSE (mild: MMSE score $\geq 20$; moderate: $10 \leq \text{MMSE score} \leq 20$; severe: $3 \leq \text{MMSE score} \leq 9$). Substituted judgement of the patients’ QoL was unrelated to severity of dementia (Table 2).

Table 2 near here

To analyze which variables related to the severity of the disease of the patient or which caregiver-related variables relate to the substituted judgement on the quality of life of the patient by the proxy we performed a stepwise regression analysis. As independent variables characterizing the severity of the disease of the patient we used the total scores of the MMSE, the patient self-assessed GDS, the Behave-AD, the Bayer-ADL, the iADL, and the frequency of drug use of the patient. As variables characterizing the well-being and health of the proxy we used the total score of the self-assessed EQ-5D and QoL-AD of the proxy, the total score of the proxy self-assessed GDS and the semantic fluency to have a measure of executive function of the proxy, and the frequency of drug use of the proxy. Both age of the patient and age of the proxy were included as independent variables in the analysis. As most important variables contributing to the caregivers’ substituted judgement of the patients’ QoL were depressivity of the patient and self-rated QoL of the caregiver.

Table 3 near here

Factor analysis of QoL-AD substituted judgement

To compare the dimensions of importance in answering the QoL-AD questionnaire when proxies report for themselves and when they perform substituted judgements a factor analysis was performed with a principal factor analysis of the QoL-AD item-level data, using an Oblim-in-direct rotation with eigenvalues greater than 1. All analyses (total group, male proxies, and female proxies) had a Kaiser-Meyer-Olkin measure between 0.8 and 0.9. For
interpretation of the rotated factors, salient loadings were defined as values greater or equal to 0.5; in cases where an item did not have a loading of 0.5 or greater, its highest loading was selected to define its position in the factor structure.

Overall, the factor structure for self-assessment and for substituted judgement resemble one another in the whole group and for both male and female proxies. Item ‘money’ is somewhat important in the proxies’ self assessment but does not come up in the substituted judgement. Similarly, item ‘memory’ is of some importance in the proxies’ self assessment but less so in the substituted judgement. General health is of similar importance in the whole group and males and females. In the male proxies’ substituted judgement this comprises household chores and doing things for fun. These items make up a separate factor in the female proxies’ substituted judgement. Moreover, marriage is a separate factor in the male proxies’ substituted judgement on the female patients QoL while in the female proxies’ judgement it is combined with item ‘family’ and ‘life as a whole.

Table 4 near here

**DISCUSSION**

*Proxy-self judgement of the proxy’s QoL*

The self-assessed quality of life of the proxy in the present study was unrelated to severity of dementia. With advancing dementia severity not only cognitive functions deteriorate but the prevalence and severity of behavioural and psychological symptoms of dementia (BPSD) increase, e.g. agitation. Previous studies reported that these symptoms are significantly associated with caregiver assessment of the patient’s QoL but not with patients’ self-assessed QoL [26,27]. Univariate analysis of BPSD and the proxies’ QoL using a different scale for assessment of BPSD, the Behave-AD, yields a clear-cut association of caregiver QoL and behavioural symptoms of dementia patients. Likewise, QoL of caregivers is inversely correlated with decline of basic and instrumental activities of daily living. As expected, there is an association of QoL in female proxies with the subjective burden
imposed by caring for a patient with dementia. However, this association was not found in males. The reasons for this gender-dependency remains elusive on grounds of the current data and needs to be addressed in future studies.

Similar to a previous study [28], depressivity is higher in female than in male caregivers and the subjective QoL is worse. Considering similar cognitive impairment and behavioural symptoms in the respective patients cared this argues for gender-dependent variables on the proxies’ side that cause the different sense of burden and impairment of quality of life imposed by the stress of caregiving.

**Substituted judgement of the patient’s QoL**

Patients’ self assessment of their own quality of life is impaired even in mild stages of dementia [2,3,29]. Likewise, assessment of the quality of life by the proxy is under discussion [2,12,30,31]. In a previous study, caregiver’s judgement of the patient’s QoL was associated with the severity of the patient’s neuropsychiatric symptoms in general and depressive symptoms in particular [32]. Moreover, dementia severity and the caregiver's depressive mood negatively affect the caregivers’ assessments of the patient’s QoL [12]. One possible alternative to be considered beyond staging disease severity and disease impact with medical outcome variables is to instruct the proxy to assume the role of the patient cared for and to give the appraisal that the patient would have given if he had been competent to do so – substituted judgement. Until now, little is known about substituted judgement on the patients’ QoL in patients with dementia.

The present analysis reveals, that substituted judgement of the patients’ QoL is modulated by proxy-related variables in a gender-dependent fashion. The stepwise regression analysis performed in this study shows that substituted judgement is subject to the self-assessed depressive mood of the patient, the proxies’ assessment of behavioural symptoms of the patient and the subjective QoL of the proxy. In a gender-specific analysis subjective QoL of the proxy is the most important variable influencing female caregivers while it is the depressivity of the patient in male caregivers.
Similarly, gender-dependent aspects were found in a factorial analysis of the QoL-AD. The literature shows two factor analytic analyses for the QoL-AD. One was performed in patients with Alzheimer’s disease [24] and one other in healthy elderly individuals [33]. The latter indicated the best fit for a three-factor solution, i.e. physical, social, and psychological well-being [34]. Applying standard factor-analytic procedures and using the Kaiser criterion the present study shows overall the best fit for a three-factor solution in proxies of patients with Alzheimer’s disease, also. Overall, there is good agreement for the factor structure of the self-assessment of the proxies’ own QoL and substituted judgement on the patients’ QoL. Gender-specific analysis, however, reveals slight differences. Female proxies have an even greater agreement for the factor structure judging their own QoL and substituted judgement on the patients’ QoL. Male proxies show some differences and the factor structure for substituted judgement shows factors that may be labelled as general- and health-related, social, and marriage. In contrast, female proxies show a factor structure which may better be labelled as general- and health-related, social, and functional.

**Conclusion**

Substituted judgement of the patient’s QoL fails to pick up dementia severity. Substituted judgment is subject to proxy-related variables in a gender-dependent fashion and therefore not suited to serve as an appropriate surrogate of the patients’ quality of life. Even the proxies’ self-assessment of their own QoL is no surrogate for picking up deterioration of the patients’ well being in patients with dementia.
COMPETING INTERESTS

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AUTHORS’ CONTRIBUTIONS

CJ, CL, and CS were involved in acquisition of the data, data analysis, and drafting and revising the manuscript. FM and MWR were involved in designing the study, interpretation of the data, and drafting and revising the manuscript. All authors approved the final version of the manuscript.

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Reference List


FIGURE LEGENDS

Figure 1: Flow chart of the study cohort.

TABLES

Table 1: Gender-specific analysis of patient and proxy-related variables grouped according to sex of the proxy.

Table 2: Patient and proxy-related variables grouped according to severity of dementia as established by results in the Mini-Mental Status Examination [13] (MMSE; mild: MMSE ≥ 20; moderate: 10 ≤ MMSE ≤ 19; severe: MMSE ≤ 9) of the proxy. ADAScog: cognitive part of the Alzheimer’s Disease Assessment Scale; GDS: Geriatric Depression Scale; QoL-AD: Quality of Life in Alzheimer’s disease [23]; Behave-AD: Behavioral pathology in Alzheimer’s Disease Rating Scale [14]; Bayer-ADL: Activities of Daily living scale [18]; iADL: Instrumental Activities of Daily living [19]

Table 3: Stepwise regression of substituted judgement of the patients’ QoL

Table 4: Factor-analysis for A) self-judgement of QoL in proxies and B) proxies’ substituted judgement of patients’ QoL
10 Drop-outs prior to / at baseline assessment (false diagnoses: n = 9; death: n = 1)

Exclusion of all patients with MMSE < 3 (N = 8)

Included
N = 212

Baseline assessment
N = 202

Analyzed
N = 194
Additional files provided with this submission:

Additional file 1: Tabellen Manuskript Qol_BMC_Neurol_28.6.11.doc, 211K
http://www.biomedcentral.com/imedia/2532931035680196/supp1.doc