Role of depressive and cognitive status in self-reported evaluation of quality of life in older people: comparing proxy and physician perspectives

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Abstract

Objective: to assess the quality of life (QOL) of older adults aged over 65 years, who were healthy or suffering from depressive syndrome (DS) and/or Alzheimer’s disease (AD); to analyse agreement between participants’ and proxies’ QOL ratings; to evaluate the association between participants’ depressive and cognitive symptoms and QOL rating; to correlate participants’ health ratings and the severity of physician assessment.

Methods: 138 non-institutionalised older people of both genders and their respective caregiver and treating doctor were consecutively recruited (response rate 74.6%). Forty suffered from AD, 36 from DS, 35 from both conditions and 27 had neither. All participants were evaluated by Mini Mental State Examination, Geriatric Depression Scale and World Health Organization Quality of Life (WHOQOL) questionnaire. The caregiver filled out QOL-Proxy and the physician filled out the ‘Health and Severity of Illness’ form.

Results: the four groups scored significantly differently in all areas of WHOQOL-100 (WHOQOL questionnaire with 100 items). Participants with DS perceived their QOL as poorer than did healthy and AD subjects. Participants with AD and DS obtained intermediate scores. Severity of depression correlated with worsening QOL. Subjects with DS—but not those with...
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AD, AD and DS, and, in some areas, healthy participants—had similar perception of their QOL to their proxies. Poor physical health ratings by the physician corresponded to poorly perceived QOL by the patient.

**Conclusion:** older people with AD perceive their own QOL similarly to and, in some areas, even better than healthy people of the same age. The opposite was observed among the depressed. Informants do not always evaluate QOL in the same way as healthy elders and those with AD, while there is more agreement with depressed patients. Informant evaluation may be helpful but is not necessarily reliable.

**Keywords:** quality of life, WHOQOL, older people, dementia, depression, informant, proxy, elderly

**Introduction**

Older people are often affected by chronic illnesses. Accordingly, health services should make efforts to improve patients’ quality of life (QOL), irrespective of disease persistence [1].

Evaluating QOL in older patients is complex [2, 3]. Some authors believe that cognitive impairment prevents persons with dementia from reliably assessing their own QOL [4–8], while others have observed that cognitive impairment does not seem to worsen subjective perception of QOL [9–11].

Applying QOL evaluation measures to subjects with psychopathological syndromes may also influence evaluation [12]. Depressed mood in particular impacts on cognitive processing, leading to a tendency to express little satisfaction in many areas of one’s own life [13]. The frequent co-existence of dementia and depressive symptoms [14] may further complicate QOL evaluation. One alternative to subjective QOL evaluation is to hear key informants.

In evaluating the QOL of demented and depressed participants, the weight of subjective versus objective measures has not been sufficiently specified.

Agreement between answers by informants and caregivers varies with different areas of QOL and selected informant [15–17].

However, while depression or cognitive decline can distort perception of QOL, it does not nullify its evaluation. Since perceived QOL is subjective, the patient’s viewpoint must be accepted. Accordingly, the World Health Organization has developed a subjective measure of QOL on the grounds that an exclusively subjective measure of QOL permits comparison of results across subject groups. Further, aspects of mental state can have a valid influence on QOL evaluation rather than impede its accurate measurement [13].

In a study in which the WHOQOL-100 (World Health Organization Quality of Life questionnaire with 100 items) was administered to patients with either moderate dementia or cancer, the former were found to have lower scores (and thus a poorer QOL) on psychological and autonomy domains and felt more physically secure and more content in terms of financial resources [18].

A shorter version of the same instrument (WHOQOL-BREF) was used by Naumann and Byrne [19] with older depressed patients. They found that three of the four domains demonstrated good reliability and validity; only the social relationships domain exhibited poor validity. In the brief version, this domain is composed of only three questions, and thus, the authors deemed it preferable to adopt the original WHOQOL-100 measure.

The aims of this study were: (i) to assess QOL of elderly patients suffering from depressive syndrome (DS) and/or Alzheimer’s disease (AD) and compare them with QOL of healthy controls using the WHOQOL-100; (ii) to analyse agreement between participants’ and proxies’ QOL ratings; (iii) to evaluate the association between participants’ depressive and cognitive symptoms and QOL rating; and (iv) to correlate participants’ health ratings and the severity assessment made by the treating physician.

**Methods**

**Sample and data collection**

All participants were consecutively recruited after their first or second referral by treating physicians based in the Veneto region (northeast Italy). Subjects had a DS—diagnosed according to DSM IV criteria at a community mental health clinic (CMHC)—or AD, or both conditions, diagnosed in one of two Alzheimer evaluation units (AEU) taking part in the CRONOS project [20]. AD diagnosis was based on the criteria used to define probable AD in the ‘CRONOS project’ [20]. At the time of assessment, the patients were not yet taking medication.

Healthy subjects were recruited at social centres and at a university for older people; all subjects who were present at one of these centres at the time of the tester’s visit were invited to take part in the research.

The key informant was identified as the person accompanying the elderly. If this person did not know the elderly person very well, they indicated who could fill out and return the questionnaire within one week. Healthy subjects were invited to do likewise. The lack of an informant meant exclusion from the study.

Eligible subjects and their proxies provided written informed consent to participate in the study.

The treating physicians for the DS and AD and AD–DS groups were two psychiatrists and three neurologists, respectively. The healthy subjects had three general practitioners (GPs).

Inclusion criteria for the four groups were based on agreement to participate in the study and on the diagnosis and scores obtained on various tests:

(i) **DS group:** Mini Mental State Examination (MMSE) score >26 and Geriatric Depression Scale (GDS) score >11.
(ii) **AD group:** MMSE between 16 and 25 (adjusted 16.4 and 24.9) and GDS <11.
(iii) AD–DS group: diagnosis of AD, MMSE between 16 and 25, GDS >11.
(iv) Healthy group: MMSE score >26, GDS score <11, scores below cut-off in all Brief Symptom Inventory (BSI) areas (indicating absence of psychiatric symptoms). Participants had not been hospitalised (for either psychiatric or somatic pathologies) during the preceding year.

**Instruments**

All participants were administered the following tests or questionnaires: MMSE [21], GDS [22], WHOQOL-100 version [12, 18, 23] and Health and Severity of Illness [24]. Healthy subjects were also administered BSI [25, 26] and informants the QOL-Proxy (QOL-P) [27]. (For more information on instruments, see Supplementary data, Appendix 1: Supplementary data are available at Age and Ageing online.)

The MMSE, GDS, WHOQOL-100, BSI and QOL-P were self-administered, with help available, where necessary, by a psychologist (GF) from the project team, who had been trained on how to approach older people and administer tests. The treating physician or GPs filled out a questionnaire on health status.

**Data analysis**

WHOQOL-100 and QOL-P scores were obtained by calculating the mean value of the answers for each of the six or five areas, respectively: the final score was then multiplied by 25 to yield a scale from 1 to 100.

To compare the four experimental groups (depression, dementia, depression and dementia and healthy subjects), variance analysis (univariate ANOVA) or the non-parametric test for independent samples (Kruskal–Wallis test) was employed. A linear regression model was used for personal variables. Post hoc tests were performed according to Bonferroni criteria, already used in the validation of the WHOQOL questionnaire.

Statistical analysis was conducted using SPSS statistical package 11.5.

**Results**

**Users**

A sample of 185 non-institutionalised elders aged over 65 years, of both sexes, was contacted. Forty-seven elders were excluded: 36 did not fulfil the inclusion criteria, 5 did not fill out the questionnaire properly, 6 declined to take part. The group of excluded subjects was older (78.61 versus 75.59; $t = 2.553; P<0.02$), but there were no differences in gender distribution.

Of the 138 included participants (response rate 74.6%), 40 had AD (mean MMSE 20.45, SD 2.41), 36 had DS (mean MMSE 27.61, SD 1.56), 35 had AD and DS (mean MMSE 21.02, SD 2.53) and 27 were ‘healthy’ (mean MMSE 28.41, SD 1.13). Mean age was 75.59 (SD ±5.184, range: 65–92 years). Females accounted for 72.5% of the sample. Mean age was 74.29 (±5.945) for men and 76.09 (±6.230) for women. (For more information on users, see Supplementary data, Appendix 2: Supplementary data are available at Age and Ageing online.)

**Proxies**

Informants were mostly females (67.9%; one missing data). Mean age was 56.11 (±13.882). Only 15 of them (11.8%) were younger than 40. Eighty-five per cent of informants were relatives; 54.3% reported living with the user. The caregivers of patients who had AD, and AD and DS more frequently lived with (62.5 and 65.7%, respectively), while only 33% of informants for healthy subjects did so ($\chi^2 = 7.974; df = 3; P<0.05$).

**QOL in the four test groups**

Significant differences ($P<0.000$) were observed among the four groups with respect to all WHOQOL-100 areas (see Supplementary data, Appendix 3: Supplementary data are available at Age and Ageing online).

Participants with DS perceived their QOL as poorer than did both the control and AD groups. Participants with AD and DS achieved intermediate scores.

Post hoc analysis showed that DS and AD–DS scores significantly differed from the other two groups in all areas except spirituality and physical domain. DS and AD–DS subjects differed in terms of general QOL (difference between means $= –11.27; P<0.05$), psychological area (difference between means $= –7.27; P<0.05$) and physical area (difference between means $= –20.43; P<0.000$).

A regression model explaining the predictive factors of QOL evaluation scores indicated that type of illness was the variable that best explained variations in QOL (as outlined more thoroughly below). Further, schooling affected the physical domain score ($F = 11.667; df = 3; P<0.000$), particularly the predictive value for those with a university degree ($t = –2.224; P<0.03$). Marital status affected psychological domain ($F = 2.69; df = 4; P<0.04$) and environment scores ($F = 3.154; df = 4; P<0.02$).

**Proxies’ versus users’ QOL rating**

Users scored higher than proxies, with significant differences in the physical ($t = 5.994; df = 137; P<0.000$), independence ($t = 5.597; df = 133; P<0.000$) and psychological domains ($t = 4.087; df = 136; P<0.000$) (see Appendix 4 in Supplementary data: Supplementary data are available at Age and Ageing online).

No significant differences were found between user and proxy ratings in the DS group only.

Among AD subjects, differences were observed in all areas, with users giving higher ratings than their caregivers (scoring differed in all areas with $P<0.001$).

Healthy subjects and those with AD and DS achieved significantly different scores in the physical ($t = 5.920; g.l. = 34; P<0.000$), higher than their proxies in both cases) and environment domains ($t = –2.518; g.l. = 34; P<0.02; higher and lower than their proxies, respectively).

**QOL and severity of depression**

Participants were subdivided according to GDS score into non-depressed (0–10), moderately depressed (11–20) and very depressed (21–30).

No area showed uniform variance; accordingly, analysis was based on a non-parametric test (Kruskal–Wallis test).

On variance analysis, the mean scores in the six areas revealed that the more severe the depression, the more
negative the QOL rating [(i) general QOL: $\chi^2 = 57.376; df = 2; P<0.000$; (ii) physical area: $\chi^2 = 17.963; df = 2; P<0.000$; (iii) psychological area: $\chi^2 = 77.370; df = 2; P<0.000$; (iv) independence: $\chi^2 = 39.374; df = 2; P<0.000$; (v) environment: $\chi^2 = 43.952; df = 2; P<0.000$; and (vi) social relations: $\chi^2 = 35.190; df = 2; P<0.000$].

**QOL and severity of cognitive decline**

According to MMSE score (adjusted by age and schooling), participants were subdivided into: unimpaired ($\geq 25; n = 63, 45.7\%$), mild cognitive decline ($24.9–21; n = 34, 24.6\%$) and moderate cognitive decline ($\leq 20.9; n = 41, 29.7\%$).

Significant differences were only exhibited in the physical area (highest score for non-impairment, lowest score for mild decline; $F = 5.205; P<0.01$) and in general QOL (highest score for moderate cognitive decline, lowest score for non-impairment; $F = 3.384; P<0.05$).

On post hoc analysis, significant differences were observed between the unimpaired and those with moderate cognitive decline ($P<0.05$). The group with mild impairment did not differ significantly from the other two.

**QOL and physician-rated health status**

According to the physicians' rating of the 132 subjects' physical health (data missing for six subjects), 29.7% were totally healthy, 26.8% presented a few symptoms, 25.4% had mild, 11.6% moderate and 2.2% severe disease.

Psychological health was evaluated as complete in 25.4%, with some symptoms present in 21%, mild disorder in 19.6%, moderate in 26.1% and severe in 3.6%.

Pooreer physical health ratings by the physicians corresponded to poorer QOL ratings by users. The mean WHOQOL score significantly changed in general QOL ($\chi^2 = 14.779; g.l. = 4; P<0.005$), psychological area ($\chi^2 = 9.639; g.l. = 4; P<0.05$), environment ($\chi^2 = 14.603; g.l. = 4; P<0.01$) and spiritual area ($\chi^2 = 12.801; g.l. = 4; P<0.02$).

Mean score analysis showed that the more severe the physician's rating of psychological illness, the poorer the users' evaluation. Significant differences were observed in all areas: general QOL ($\chi^2 = 38.435; g.l. = 4; P<0.000$), physical area ($F = 3.160; g.l. = 4; P<0.02$), psychological area ($\chi^2 = 62.552; g.l. = 4; P<0.000$), social relations ($F = 7.974; g.l. = 4; P<0.000$), environment ($F = 13.400; g.l. = 4; P<0.000$), independence ($\chi^2 = 9.639; g.l. = 4; P<0.05$) and spiritual area ($F = 7.266; g.l. = 4; P<0.02$).

**Discussion**

To the best of our knowledge, this is the first study to assess QOL by a subjective instrument—the WHOQOL-100—and by one for informants derived from it—the QOL-P—in four elderly populations affected by dementia or depression or both, and healthy peers. (For more information on strengths and weaknesses of the article, see Appendix 5 in Supplementary data: Supplementary data are available at Age and Ageing online.)

In our research, comparison of the mean scores of the four groups for the different QOL areas assessed by WHOQOL-100 has shown that depression and cognitive impairment influence subjective evaluation differently (Figure 1).

As stressed in other studies on institutionalised and community-dwelling elderly [8, 19], depression is correlated with a negative evaluation of QOL.

Depressed persons achieved lower mean scores than 'healthy' and demented subjects. The AD–DS group score lay between the one achieved by those with depression or dementia only. This trend was observed in all areas of QOL, including spirituality, suggesting that personal beliefs and religious ideas are also perceived more negatively in the depressed.

Naumann and Byrne [19], who measured depression by a dimensional approach, also found a correlation: the more severe the depressive symptoms, the lower the scores on the WHOQOL-BREF.

Generally speaking, cognitive impairment does not seem to worsen subjective perception of QOL. We found the scores obtained by demented elderly to be no different from those of ‘healthy’ subjects and in some areas (general QOL, independence and social relations) to be even better. This supports previous studies, such as the one by Ready et al. [9] who reported no significant differences between self-reported QOL by AD and controls, or Nagatomo [11] who stressed that elderly QOL is not influenced by degree of cognitive impairment. Further, Lyketosos and colleagues [10] maintained that a substantial number of people with advanced dementia do not experience a decline in QOL over time.

Our research also considered degree of overlap in subjective and objective QOL ratings by key informants.

In a review on the role of significant others in QOL evaluation in the chronically ill, Sprangers and Aaronson [17] reported low levels of agreement, emphasising the limited reliability of this evaluation method as an alternative to interviewing subjects. Ready et al. [9] stressed that informant and self-perceptions of QOL in AD, mild cognitive impairment and older adult controls differed substantially and suggested considering both sources because they provide unique information on patient QOL and neither has yet been established to be superior.

We also revealed a discrepancy between the ratings of caregivers and demented subjects in all QOL areas and in the Physical and Environmental areas in those with both dementia and depression, despite the fact that users and caregivers frequently lived together in these two groups. Overall, caregivers—who in roughly half the cases, cohabited with the patient (54.3%)—provided a more negative evaluation even though some areas, such as environment and social relations were rated similarly.

A previous study suggested that ratings by key informants in more observable areas, such as physical cognitive functioning, are more highly correlated with those of the patient [17]. As for functional impairment, key informants tend to consider patients to have more severe deficits (overstating the degree of malfunctioning compared to the patient); this is particularly true of informants living in close contact with the patient [17]. On the other hand, patients tend to report more difficulties in other domains [10, 15, 16].

Boyer et al. [28] suggested that, quite surprisingly, non-family members were better proxies because they more closely reflected the patient’s opinion, except for assessment
of physical mobility. Family members over-estimated impairment in the isolation, sleep, emotional reactivity and energy dimensions. These are precisely the domains that involve burden for family proxies.

The discrepancy between demented patients and their caregivers may be explained by assuming that, in addition to cognitive decline, users lose the ability to perceive their own outside (environment, relations etc.) and inner world (physical and psychological areas). Conversely, caregivers may underestimate QOL, possibly influenced by the stigma of dementia, or caregiver stress may condition assessment quality. Nevertheless, the caregiver of a depressed patient may in turn be depressed and underestimate the QOL of the person in their care.

Conceivably, those with a relative who is affected by AD experience the situation more strongly than the participants themselves and the weight of this disease on QOL overshadows the possibility of expressing a judgement that respects the participant’s actual feelings. Evaluating the effect of dementia stigmatisation may provide significant information in this respect.

In the present study, discrepancies also emerged between ‘healthy’ subjects and their caregivers in evaluation of physical and environment areas, confirming the need for caution when evaluating QOL based solely on results given by proxies [9].

However, no discrepancy was found between subjective evaluation and caregiver rating for participants with depression.

As regards the opinions expressed by the treating physicians, the most influential factor proved to be degree of psychological illness (as expected, given the impact of depression), positively correlating with a worse QOL score in nearly all domains.

What is clear, beyond the results and observed differences, is that demented elders, like depressed or ‘healthy’ ones, can assess their own QOL. What remains to be determined is how far dementia can progress before this is no longer possible and therefore advisable.

**Conclusions**

Differences in evaluation observed for subjects with AD versus depressed patients suggest that two different approaches are required with these patients with respect to their QOL.

Our research reveals that Alzheimer patients perceived their own QOL rather like ‘healthy subjects’ and in some areas even better, whereas depressed elderly provided a negative rating.

More research work is warranted on the role of key informants in reporting on patients’ QOL. Informants’ and patients’ judgements tended to contrast, especially where the patient was demented but also a healthy subject. This might indicate that, while those who are in close contact with the subject have common experiences, their subjective nature prevents them from being fully shared. Although
people with AD lack insight into the effects of cognitive decline on experience or even forget experiences, we wonder whether it would be legitimate not to give priority to their subjectively perceived QOL.

Key points

- Subjects with depression achieved lower mean QOL scores than healthy subjects and those with AD. The scores of those with DS and AD were intermediate.
- The more severe the depressive symptoms the lower the scores.
- The discrepancy between users and caregiver/proxy ratings covered all QOL domains for demented patients, some domains for healthy subjects, while there was complete convergence for depressed patients.

References