Health-related quality of life in carers of patients with dementia

Josep M Argimon⁹, Esther Limon⁹, Joan Vila⁹ and Carmen Cabezas⁹


**Background.** Carers of patients with dementia experience high levels of stress that can adversely affect their health and well-being.

**Objective.** Our aim was to assess the health-related quality of life of carers of patients with dementia compared with an age- and gender-matched sample from the general population.

**Methods.** A cross-sectional study was conducted in 37 primary health care centres in Catalonia, Spain. Carers (n = 181; 78% females, mean age 63 years) of patients with dementia together with a random sample of 543 individuals from the general population, matched for age and gender, were assessed with the SF-36 questionnaire, which is a generic measure of health status.

**Results.** With the exception of physical function category, seven of the scales showed lower scores for females in the carer group. The most important differences were observed in the emotional role [95% confidence interval (CI) 37.7 to 3.6], mental health (95% CI 21.0 to 1.6) and bodily pain (95% CI 37.7 to 8.6) categories. In contrast, male carers had higher scores in the physical function category (95% CI 2.2–19.4), and no differences were observed on the other scales.

**Conclusion.** Female carers of patients with dementia experienced a seriously decreased quality of life level compared with their contemporaries in the general population.

**Keywords.** Carer, dementia, psycho-geriatric, quality of life, questionnaire.

**Introduction**

Over time, patients with dementia invariably decline in cognitive and functional status, and most develop behavioural disturbances, whether early or late in the clinical course of the disease. As patients’ dependency on assistance increases, the level of strain on the carer rises. The carer may develop feelings of anger, grief, loneliness and resentment, with the result that the health and well-being of the carer are adversely affected.

The impact of the patient’s dementia on the carer has been conceptualized, most often, in terms of carer burden. However, as a measure of carer outcomes, the concept of burden has been questioned because it has both subjective and objective qualities, regarding which there is a lack of consensus as to what differentiates between these two aspects in the description of burden.¹ An alternative that has been employed frequently is an evaluation of psychological well-being that, in turn, is a central component of the health-related quality of life (HRQoL). Evidence exists confirming the conceptual distinctiveness of burden and of well-being.² The suggestions following from these studies have been that the HRQoL of carers can be improved despite their burden. Many instruments have been proposed and evaluated for the measurement of HRQoL, and have been either disease specific or generic. The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)³ is a generic instrument that has been used widely in several countries, with different population groups and with different disease states. It has been translated and validated in many languages, including Spanish.⁴

The purpose of the present study was to assess the HRQoL of carers of patients with dementia and to compare the data with those from age- and gender-matched control subjects from the general population.
Subjects and methods

A cross-sectional study was conducted in 37 primary health care centres in the metropolitan area of Barcelona (Catalonia, Spain) and its environs, and with a health care remit covering 740,000 inhabitants. These 37 centres were those from 239 within the Area Health Authority and who accepted our offer to participate. Each centre recruited the carers of the first five patients with dementia visited during the specific period of patient–carer recruitment, and who agreed to participate. The study population was composed of the informal carer who, according to the family, was the person (other than a health care professional) who normally took most responsibility for day to day decisions and the provision of home care for the patient. We excluded carers who undertook this responsibility of providing care for the patient for <6 months of the year. Patients had a clinical diagnosis of primary degenerative, multi-infarct or mixed dementia, and had been classified as being moderately to severely impaired. The patient’s overall severity of dementia was determined by the Global Deterioration Scale (GDS), a semi-structured rating of a patient’s functional status based on interview with the carer at the start of the study. Patients with dementia usually score between 4 and 7 on this scale. The patients were classified within a 12–24 month period prior to the start of the study. The carers who satisfied the eligibility criteria were invited to participate in the study and were recruited over a period of 6 months. A family physician in each primary health care centre, with a special interest in dementia, assessed the eligibility criteria of the patient and obtained the informed consent of the carer for participation in the study.

Instruments of measurement

The socio-demographic data were obtained from a structured questionnaire. HRQoL was assessed with the SF-36, a generic instrument of health status measurement that contains 36 questions. The SF-36 assesses eight dimensions of health status and spans a spectrum of qualities of physical as well as mental health. In order to facilitate comparisons with other population studies, items from each concept were summed, and re-scaled with a standard range of 0–100 in increasing order of quality of health content. The eight SF-36 scales are aggregated into two component summary scales; a physical component and a mental component summary, based on distinct physical and mental constructs.

The questionnaire was administered by a trained interviewer at the carer’s home. To assess the impact of caring given on the different scales, standardized scale scores were contrasted with the Spanish normative data on 9151 individuals of ≥18 years of age. The data were obtained in a cross-sectional study of a multistage stratified random sample of non-institutionalized individuals. Three subjects were selected randomly from this database to match each carer for age and gender.

Statistical methods

The descriptive statistics are presented as means and SDs. The mean differences between groups for all scales were computed. For variables that were not normally distributed, the Mann–Whitney U-test was used to compare independent groups.

To standardize the scores, the difference between the carers’ raw score and the mean score of the reference group was calculated. This difference was then divided by the standard deviation of the control group. These standard scores (z-scores) express the individual's distance from the reference group in terms of the distribution (effect size). Any score equal to the mean of the reference group will be equivalent to an effect size of zero. Negative or positive values result from individuals falling below or above the mean, respectively.

Since question 2 of the SF-36 does not form part of the final score and refers to the change in health over a period of time, the data from these scores were analysed separately. The question was whether the respondent’s general health was much better, somewhat better, stayed the same, was somewhat worse or much worse compared with the previous year.

The SPSS program (version 10 for Windows) was used for the tabulation and statistical analysis of the data.

Results

The study objectives were presented to the 210 carers, and 25 of them chose not to participate. A total of 185 care givers agreed to participate, but with four of them we were unable to establish contact following the initial agreement to participate. Of the 181 who agreed to participate, 78% were female. Of the total, 54% were aged over 65 years (mean 63 years, SD = 12) and 40% had 8 years of formal education. The carers were spouses or adult relatives who lived, or spent a minimum of 4 h per day, with the patient. Of the patients in their care, 52% were clinically diagnosed as having Alzheimer’s disease, 25% vascular dementia and 23% mixed dementia. The mean duration of the disease at the time of the study was 4 years (SD = 3).

The results of the SF-36 segregated with respect to carer gender and compared with the control group data are presented in Tables 1 and 2. With the exception of physical function, seven of the scales showed lower scores (worse health) for females in the carer group. The most important differences were observed in the role emotional [95% confidence interval (CI) −37.7 to −3.6], mental health (95% CI −21.0 to −1.6) and bodily pain (95% CI −37.7 to −8.6) categories. The effect size of the standardized mental component score (95% CI −12.8 to −7.7) was 90% of 1 SD worse than that of the sample
from the general population. In contrast, male carers had higher scores on the physical functioning scale (95% CI 2.2–19.4), and no differences were observed on the other scales.

In 37.6% of the female carers, the respondents indicated that their health was worse or much worse than the previous year, compared with 26.2% of the females in the control group ($P = 0.007$). In the males, the differences were not statistically significant (21.6% of the male carers compared with 20.7% of the males in the control group).

**Discussion**

The findings of the present study highlight a reduced HRQoL in female carers of patients with dementia.

The study has some limitations. First, as far as we know, the SF-36 has not been validated with respect to carers of patients with dementia. Secondly, of note are the large standard deviations observed in the scales scoring for emotional and physical roles. These findings have been observed by other authors in other populations and could be explained, in part, by the

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**Table 1** Mean values and SDs on the eight SF-36 scales in the female subgroup of carers compared with a sample of females from the general population, matched for age

<table>
<thead>
<tr>
<th>Scale</th>
<th>Female carer (Mean, SD)</th>
<th>Control (Mean, SD)</th>
<th>95% CI</th>
<th>Size effect</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>73.8 (21.0)</td>
<td>72.8 (27.3)</td>
<td>-3.3 to 5.4</td>
<td>0.04</td>
<td>0.64</td>
</tr>
<tr>
<td>Physical role</td>
<td>65.4 (38.7)</td>
<td>73.8 (41.0)</td>
<td>-15.9 to -8.6</td>
<td>-0.20</td>
<td>0.03</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>44.7 (33.2)</td>
<td>68.6 (31.4)</td>
<td>-30.2 to -17.6</td>
<td>-0.76</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General health</td>
<td>54.0 (24.9)</td>
<td>58.1 (23.3)</td>
<td>-8.6 to 0.4</td>
<td>-0.18</td>
<td>0.07</td>
</tr>
<tr>
<td>Vitality</td>
<td>49.3 (29.0)</td>
<td>59.6 (24.6)</td>
<td>-15.5 to -5.2</td>
<td>-0.42</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Social functioning</td>
<td>73.8 (35.5)</td>
<td>84.8 (24.4)</td>
<td>-16.2 to -5.7</td>
<td>-0.45</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Emotional role</td>
<td>53.0 (42.6)</td>
<td>83.6 (34.9)</td>
<td>-37.7 to -3.6</td>
<td>-0.88</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mental health</td>
<td>51.3 (25.3)</td>
<td>67.7 (22.6)</td>
<td>-21.0 to -1.6</td>
<td>-0.73</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SPC</td>
<td>46.1 (10.0)</td>
<td>45.4 (11.1)</td>
<td>-1.4 to 2.7</td>
<td>0.06</td>
<td>0.54</td>
</tr>
<tr>
<td>SMC</td>
<td>38.3 (16.0)</td>
<td>48.6 (11.5)</td>
<td>-12.8 to -7.7</td>
<td>-0.90</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

$^a$ Calculated by Mann–Whitney’s U-test.

SPC = standardized physical component; SMC = standardized mental component.

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**Table 2** Mean values and SDs on the eight SF-36 scales in the male subgroup of carers compared with a sample of males from the general population, matched for age

<table>
<thead>
<tr>
<th>Scale</th>
<th>Male carer (Mean, SD)</th>
<th>Control (Mean, SD)</th>
<th>95% CI</th>
<th>Size effect</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>81.1 (21.6)</td>
<td>70.3 (29.0)</td>
<td>2.2 to 19.4</td>
<td>0.37</td>
<td>0.01</td>
</tr>
<tr>
<td>Physical role</td>
<td>79.4 (37.5)</td>
<td>78.5 (40.0)</td>
<td>-13.1 to 14.7</td>
<td>0.02</td>
<td>0.90</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>69.6 (36.9)</td>
<td>77.5 (29.7)</td>
<td>-19.3 to 3.5</td>
<td>0.26</td>
<td>0.22</td>
</tr>
<tr>
<td>General health</td>
<td>61.3 (23.8)</td>
<td>55.1 (24.9)</td>
<td>-2.6 to 15.0</td>
<td>0.25</td>
<td>0.16</td>
</tr>
<tr>
<td>Vitality</td>
<td>65.8 (34.5)</td>
<td>60.7 (25.1)</td>
<td>-7.7 to 13.8</td>
<td>0.12</td>
<td>0.57</td>
</tr>
<tr>
<td>Social functioning</td>
<td>82.5 (31.4)</td>
<td>88.2 (23.3)</td>
<td>-15.0 to 3.5</td>
<td>-0.27</td>
<td>0.22</td>
</tr>
<tr>
<td>Emotional role</td>
<td>78.3 (39.6)</td>
<td>86.4 (33.6)</td>
<td>-20.7 to 4.6</td>
<td>-0.24</td>
<td>0.21</td>
</tr>
<tr>
<td>Mental health</td>
<td>66.4 (28.5)</td>
<td>71.2 (22.4)</td>
<td>-14.2 to 4.5</td>
<td>-0.21</td>
<td>0.30</td>
</tr>
<tr>
<td>SPC</td>
<td>48.6 (11.8)</td>
<td>45.6 (10.8)</td>
<td>-1.5 to 7.3</td>
<td>0.28</td>
<td>0.18</td>
</tr>
<tr>
<td>SMC</td>
<td>46.2 (15.3)</td>
<td>49.7 (10.8)</td>
<td>-8.2 to 1.2</td>
<td>-0.32</td>
<td>0.14</td>
</tr>
</tbody>
</table>

$^a$ Calculated by Mann–Whitney’s U-test.

SPC = standardized physical component; SMC = standardized mental component.
large numbers of subjects with high percentage scores at the extreme ends of the scale (the ‘ceiling and floor’ effect). The proposed solution has been to include more response categories for the items in these two subscales so as to have a gradation of role disability evaluation, rather than the current categorical response of ‘presence’ or ‘absence’ of disability. Thirdly, there is the possibility of a selection bias, but this may be negligible. For example, the carers recruited were from among those providing care for patients with dementia who are supervised in a primary health care centre. However, the health system in Catalonia is a public one with universal cover and, hence, almost no patient with this clinical condition would be outside the health care system. The patients attended the primary health care centres with a mean frequency of six visits per year.

Mental health and emotional role are the scales that are most closely related to the standardized mental component. The scores reported by female carers on both of these scales are located at a considerable distance from the scores of the age- and gender-matched control individuals. This concurs with other reports of psychological distress in carers of patients with dementia, and in whom the prevalence of depressive disorders has been reported to be ~43%. In EUROCAR, a study aimed at producing a cross-European Community profile of the co-resident spouse carer, there was marked variation in many variables of interest between countries. However, there was a consistently high rating for psychological distress, with between 40 and 75% of responses scoring 4 or more on the General Health Questionnaire-12.

Female carers also score worse than the general population in terms of bodily pain, vitality, general health, physical role limitations and social function categories. Also, in the mental health component summary, they have a profile that describes a generally poor HRQoL.

The only significant difference in male carers was in the physical function scale category in which the carers appeared to have better scores than their counterparts in the general population. Incidentally, this scale is the only one not affected in female carers. An explanation could be that carers need to maintain good physical function levels so as to be able to provide an adequate level of care for the patient in their charge.

More than a third of the female carers indicated that their health had deteriorated, or very badly deteriorated, from the previous year. This is of considerable importance because it is an item of health self-assessment that has been reported, consistently, as being associated with mortality, even following the statistical adjustment for a wide range of health measurements and known mortality risk factors.

The strain of care giving has been associated with adverse physiological and psychological outcomes for carers and has even been identified as a mortality risk factor among carers. In addition, the level of burden on the carer has been used to predict potential institutionalization requirements for the carer. As such, it is important to examine the effects of care-giving responsibility on the carer’s HRQoL.

Future research should focus on identifying interventions that may prevent, or minimize, the worsening of HRQoL in care givers. An informal carer occupies an important position within the community in terms of health and social care policy. In most Western countries, placing a patient under institutional care is seen as a last resort. To be able to care for the patient within the home environment for as long as possible, it is essential to preserve the carer–patient relationship while at the same time reducing the care giver’s own health risks.

Acknowledgements

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References