

Cognitive impairment, dementia and quality of life in patients and caregivers

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Abstract

Objective : To study the impact of cognitive impairment and severity of dementia on the quality of life (QoL) of patients and their caregivers.

Design : descriptive cross-sectional study within the National Dementia Economic Study.

Setting : 231 general practices and 15 specialist clinics in Belgium.

Subjects : 605 patients aged ≥ 65 years : 106 referent subjects without cognitive impairment (R), 113 subjects with cognitive impairment and no dementia (CIND), 386 subjects with mild (83), mild/moderate (108), moderate (62) or severe (133) dementia (D1 to D4).

Outcome measures : QoL of patients : COOP/WONCA charts, Katz's Activities of Daily Living (ADL) scale, Lawton's Instrumental Activities of Daily Living (IADL) scale. QoL of caregivers : COOP/WONCA charts, SF-36 questionnaire, short-form Beck Depression Inventory, Sense of Competence questionnaire (SCQ).

Main results : QoL of patients : For R, CIND and D1 to D4 patients, dependence for ADL reached 5%, 6%, 16%, 20%, 48% and 79%, respectively, and mean IADL scores were 5.6, 5.0, 3.4, 2.0, 0.6 and 0.1, respectively.

QoL of caregivers : The main impact of caregiving was on mental health, with SF-36 MCS scores of 51.3, 47.7 and 45.4 for R, CIND and all D patients and respectively 32.6%, 31.3% and 42.5% depression prevalence. Sense of competence decreased with severity of patient's cognitive impairment. Caregivers of CIND patients always rated intermediate between R and D1 patients. Caregivers of D3 patients were the most affected ones.

Conclusion : The data suggest that improving the cognitive status of patients and providing assistance to caregivers would be complementary ways of action to support caregiving of patients living at home.

Introduction

With the ageing of the population, dementia represents an increasing medical and socio-economic burden. According to epidemiological studies, the prevalence of dementia in people aged ≥ 65 varies between 5% and 20%. In Belgium, a prevalence of dementia of 14.3% was found among elderly patients ≥ 65 years living at home and consulting in general practice, with a prevalence figure

of 11.3% extrapolated to the elderly population in Belgium (Kurz *et al.*, 2001). An economic analysis in patients with dementia concluded that providing services and caring for patients at home do not represent expensive activities in absolute terms (about 100 € per patient and per month). They actually amount to only a small fraction of the medical costs spent by the health system for the caring of demented patients, even if unpaid assistance is valued (Scuvée-Moreau *et al.*, 2002).

From an economic point of view, these figures support the caring for the patient at home. However, providing care at home means that family members and/or friends are available and able to support this burden. In Belgium, like in other countries, the majority of patients with dementia live at home (Vandenbroele *et al.*, 1994). In most cases, there is a main caregiver who takes over the burden of caring and surveillance. These tasks are often associated with reduced quality of life (QoL), assessed on the basis of scores obtained for measures of physical, psychological, emotional and social functioning. Depression was the medical disorder most often found in studies (Fiore *et al.*, 1983, Schulz *et al.*, 1990, Ballard *et al.*, 1995, Livingston *et al.*, 1996, Karlawish *et al.*, 2001), even if it is still unclear whether it is actually caused or aggravated by the burden of caregiving. Other consequences on mental health have been anxiety, psychological distress and social isolation (Schulz *et al.*, 1990, Walker *et al.*, 1998, Bell *et al.*, 2001). In addition, an association between the severity of dementia and the QoL of patients and caregivers has been shown in several studies (Winblad *et al.*, 2000, Albert *et al.*, 2001, Karlawish *et al.*, 2001, Zank and Leipold, 2001).

There is a growing interest for patients with cognitive impairment and no dementia (CIND). This condition may indeed have a wide spectrum of cognitive impairment bordered by normal cognitive performances on one end and established dementia on the other. As it may represent an early

* Members of the NADES Group are listed in Kurz *et al.* 1999.

stage of dementia, investigation of the functional impact of CIND allows to examine the QoL impact of a prodromal stage of dementia, helps identify patients who can either progress to dementia or improve, and enables to measure the extent to which caregivers are affected by cognitive impairments of patients (Visser *et al.*, 2000, Tuokko *et al.*, 2001, Albert *et al.*, 2002, Palmer *et al.*, 2002, Rapp *et al.*, 2002, Tabert *et al.*, 2002).

Using a same study population and the same survey instruments, this study investigates the QoL of elderly people without cognitive disorders, with cognitive impairment and no dementia (CIND), and with dementia of differing severity. The study also examines whether the QoL of patients is more affected by the level of cognitive impairment than by the disease itself, and investigates the relationship between the cognitive functioning of patients and the QoL of caregivers.

Patients and methods

STUDY DESIGN

This study is a descriptive cross-sectional study using data collected at baseline in the NATIONAL Dementia Economic Study (NADES), a prospective one-year study on the socio-economic impact of dementia in 605 patients recruited by general practitioners and specialists in Belgium (Kurz *et al.*, 1999). A total of 231 general practitioners, 15 specialists and 20 psychologists throughout Belgium participated in the study. In a first stage, 2784 patients aged ≥ 65 years consulting general practitioners (regardless of the reason for consultation) were registered and screened for the presence or absence of 10 warning signs of dementia. In a second stage, a sample of these patients and a sample of patients diagnosed by specialists were selected to have a CAMDEX (Roth *et al.*, 1986) administered at home by trained psychologists. The validation of the diagnosis of dementia was performed with an algorithm designed by a panel of neurologists on the basis of the criteria of DSM-III-R ascertained from CAMDEX data (Kurz *et al.*, 1999). Data for dubious cases were independently reviewed by at least two neurologists. Patients with at least 3 warning signs but without a diagnosis of dementia were classified in the "cognitive impairment, no dementia" (CIND) category. Patients with a diagnosis of dementia were classified by level of severity of dementia based on the MMSE score extracted from the CAMDEX. This procedure allowed to create six mutually exclusive cohorts: a cohort of referent subjects without cognitive impairment ($n = 106$), a cohort of subjects with cognitive impairment but no dementia (CIND) ($n = 113$), and four cohorts of demented patients with mild (MMSE score ≥ 21 , $n = 83$), mild to moderate (MMSE score 15-20, $n = 108$), moderate

(MMSE score 10-14, $n = 62$) or severe (MMSE score < 10 , $n = 133$) dementia. Among demented patients, 218 lived at home and 168 lived in institution. No referent patients and no CIND patients were recruited in institutions.

DATA COLLECTION

For referent, CIND and demented patients living at home, the presence of a main caregiver was identified at the first visit to the patient's home. QoL measures for patients and the main caregiver were performed by face-to-face interview, at baseline and during each of three follow-up visits. In case a main caregiver was identified but did not attend the visit, all results were put as missing for that visit (there was no replacement visit or attempt to interview the caregiver by telephone). In case a patient died or exited the study, no further interview of the caregiver was performed. In order to ensure simultaneity between the evaluations of the cognitive status of patients and the QoL of patients and caregivers, the analyses presented in this study are based on the QoL data collected at the first home visit made by psychologists, during which the CAMDEX was also administered. This rule does not apply to the Lawton's scale of Instrumental Activities of Daily Living (see below), which was first applied to patients at the second visit, due to the large number of questions asked at the first visit. Therefore, there was a delay of about 6 months between the classification of the clinical status of patients and the measure of the Lawton's Instrumental Activities of Daily Living. Caregivers who were only identified and interviewed in a follow-up visit are therefore not included in the analyses of the QoL of caregivers.

For patients living in an institution, the presence of a caregiver who regularly visited the patient was identified with the patient or the institution's staff. The caregiver was reached and interviewed by telephone by a psychologist.

OUTCOME MEASURES

Patients

- The COOP/WONCA charts, which include a pictorial representation of questions and response categories, were used as a generic QoL instrument measuring six dimensions of the functional status: physical fitness, feelings, daily activities, change in health and overall health (Nelson *et al.*, 1987; van Weel, 1993). Possible values ranged from 1 to 5, the highest score indicating the worst result.
- Activities of daily living (personal care, clothing, moving, going to the toilet, eating) were measured with the Katz scale (Katz *et al.*, 1963) and assessed if necessary with the spouse or

another caregiver. According to the INAMI/RIZIV criteria used in Belgium, patients were rated as non-dependant or dependant globally and separately for each activity.

- The Lawton's assessment scale was used to assess abilities in instrumental activities of daily living (IADL), such as giving phone calls, shopping, driving and using money (Lawton and Brody, 1969). The scores range from 0 (worst result) to 7 (best result). Results for demented patients in institution are not presented as most of them do not have access to these activities.

Caregivers

- Generic QoL was assessed with the COOP/WONCA chart and the Short Form Health Survey-36 (SF-36) (Ware and Gandek, 1998), a 36-item questionnaire that measures eight health dimensions (physical and social functioning, role limitations due to physical and emotional problems, mental health, vitality/energy, pain, and general health perceptions) in three areas (functional status, well-being, overall evaluation of health). The Physical Component Summary Score (PCS) and the Mental Component Summary score (MCS) calculated from the SF-36 were used as outcome measures. They are standardized to the general population of the United-States, with a mean of 50, a standard deviation of 10 and a range of 0-100.

Measures of depression and sense of competence were used as specific measures of QoL in caregivers.

- Depression was assessed with the short-form Beck Depression Inventory (Beck and Beck, 1972 ; Knight, 1984). According to the score obtained, patients were rated as having none or minimal depression (0-4), mild depression (5-7), moderate depression (8-15) or severe depression (16-39) (Beck and Beck, 1972).
- The psychological burden of caring for the patient was assessed with the Sense of Competence Questionnaire (SCQ) (Vernooij-Dassen, 1993), a validated instrument based on the family-crisis model (Bengston and Kuypers, 1985) and derived from Zarit's Burden Interview (Zarit *et al.*, 1980). The SCQ distinguishes three dimensions : satisfaction with the elderly person as recipient of care (5 items, range of scores : 0-7), satisfaction with one's own performance as caregiver (12 items, range of scores : 0-12), and consequence of involvement in care for the personal life of the caregiver (8 items, range of scores : 0-8). For each dimension, higher scores indicate a higher sense of competence. A total score (range : 0-27) encompasses the three dimensions. As it existed in Dutch only, it was translated into French for use in the NADES study. A standard translation-backtranslation

procedure was performed in order to test the accurateness of the French version. Its validity and reliability were formally tested and showed results within the normal range (Vernooij-Dassen *et al.*, submitted). The SCQ was the only QoL questionnaire administered by telephone to caregivers of patients living in institution.

STATISTICAL ANALYSES

The sample size of the NADES study was initially based on assumed differences in economic outcomes between the different cohorts. It was not adequate for testing small differences in QoL scores. In addition, many QoL outcomes are interrelated, and the results of multiple non independent comparisons would be difficult to interpret. Therefore, no formal statistical tests were performed in this study. However, all mean values are presented with their respective sample size and standard deviation.

Results

STUDY POPULATION

Patients

The patient population has been previously described (Kurz *et al.*, 1999 ; Scuvée-Moreau *et al.*, 2002). The majority of subjects (59.4% of nondemented and 43.2% of demented patients) were in the age range 75-84 years, with a mean age of 78.1 years among nondemented patients (median : 78.0, range : 65-93) and of 81.2 years among all demented subjects (median : 81.0, range : 65-100). Women represented 52.5% of nondemented patients and 71.0% of patients with dementia. The proportion of French and Dutch-speaking patients was comparable in the different cohorts (52% versus 48% overall). More nondemented than demented patients had an education level higher than the primary school (respectively 42.0% and 25.1%).

Caregivers

For 207 patients living at home and 122 patients living in an institution, there was a main caregiver at the time of the first visit. Among the 80.4% of caregivers living at home with the patients, 75.9% were the patient's wife or husband, and 65.3% were females (Table 1). The mean age was 73.4 years for caregivers of referent patients, 70.1 years for those of CIND patients and 70.0 years for those of demented patients. Among the caregivers living in a separate residence, 80.3% were female and 62% were the patient's son or daughter. The mean age was 52.8 years, 52.0 years and 54.9 years, respectively, for caregivers of referent, CIND and demented patients. For 192 of the 207 patients living at home, the caregiver could be interviewed. A care-

Table 1
Socio-demographic profile of caregivers of patients living at home

	Referent patients (no cognitive impairment)	Patients with CIND	Patients with dementia				
			mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
N caregivers	72	83	59	78	33	37	207
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
<i>Cohabiting caregivers</i>	57 (79.2)	70 (84.3)	44 (74.6)	58 (74.4)	29 (87.9)	33 (89.2)	164 (79.2)
<i>Gender</i>							
Male	15 (26.3)	24 (34.3)	21 (47.7)	20 (34.5)	10 (34.5)	11 (33.3)	62 (37.8)
Female	42 (73.7)	46 (65.7)	23 (52.3)	38 (65.5)	19 (65.5)	22 (66.7)	102 (62.2)
<i>Age</i>							
mean (s.d.)	73.4 (9.5)	70.1 (11.9)	73.4 (8.9)	69.2 (12.7)	67.3 (12.9)	69.2 (11.7)	70.0 (11.7)
<i>Relation to patient</i>							
Wife/husband	45 (79.0)	56 (80.0)	36 (81.8)	32 (55.2)	19 (65.5)	24 (72.7)	111 (67.7)
Sister/brother	1 (1.7)	0	1 (2.3)	3 (5.2)	0	0	4 (2.4)
Daughter/son	7 (12.4)	5 (7.1)	3 (6.8)	14 (24.1)	8 (27.6)	6 (18.2)	31 (18.9)
Other	4 (7.0)	9 (5.7)	4 (9.1)	9 (15.5)	2 (6.9)	3 (9.1)	18 (11.0)
<i>Non cohabiting caregivers</i>	15 (20.8)	13 (15.7)	15 (25.4)	20 (25.6)	4 (12.1)	4 (10.8)	43 (20.8)
<i>Gender</i>							
Male	4 (26.7)	3 (23.1)	3 (20.0)	4 (20.0)	0	0 (0.0)	7 (16.3)
Female	11 (73.3)	10 (76.9)	12 (80.0)	16 (80.0)	4 (100.0)	4 (100.0)	36 (83.7)
<i>Age</i>							
mean (s.d.)	52.8 (12.7)	52.0 (10.1)	52.7 (13.8)	59.4 (11.7)	47.0 (3.0)	48.5 (4.6)	54.9 (12.2)
<i>Relation to patient</i>							
Sister/brother	0	1 (7.7)	0	3 (15.0)	1 (25.0)	0 (0.0)	4 (9.3)
Daughter/son	10 (66.7)	10 (76.9)	9 (60.0)	8 (40.0)	3 (75.0)	4 (100.0)	24 (55.8)
Other	5 (33.3)	2 (15.4)	6 (40.0)	9 (45.0)	0	0	15 (34.9)

CIND : cognitive impairment, no dementia.
s.d. : standard deviation.

giver could be interviewed for 122 patients living in institution (Table 2) ; 63.9% of them were female and 56.6% had a filial relationship with the patient. Their mean age was 59.2 years.

QoL OF PATIENTS

COOP/WONCA chart

Up to 25% of moderately demented patients and 75% of severely demented patients were not able to answer at least one question of this chart, despite its pictorial representation of questions and answers. The results have therefore a limited value. Overall health had mean scores of 2.9, 3.3 and 3.1 for referent, CIND and demented patients, respectively. No or very small differences were observed between the different cohorts for any dimension of functional status.

Activities of daily living

Dependence for activities of daily living was observed for up to 6% and 7% of referent and CIND patients, while the percentage of dependence in patients with dementia increases with the severity of the disease (Table 3). For all demented patients, dependence ranged from 14.5% for eating

to 44.0% for clothing. The percentage of patients with mild dementia was more than twice higher than that of CIND patients.

IADL

A marked difference in the mean score was observed between the different cohorts. The mean values (standard deviation) were 5.6 (1.4) and 5.0 (1.7) for referent and CIND patients, and 3.4 (2.2), 2.0 (2.0), 0.6 (1.0) and 0.1 (0.4) for patients with mild, mild to moderate, moderate and severe dementia. The score was 2.0 (2.2) for all demented patients.

QoL OF CAREGIVERS

COOP/WONCA chart

Overall health scores were relatively worse for caregivers of demented patients living at home (mean 3.0, s.d. 0.9) than for caregivers of referent (mean 2.8, s.d. 0.8) or CIND patients (mean 2.8, s.d. 0.8), the worst score being observed for caregivers of patients with severe dementia (mean 3.2, s.d. 0.7). Social life was also rated worse by caregivers of moderately demented patients (2.6) than for the other cohorts. No differences were observed between the different cohorts for the other dimensions.

Table 2
Socio-demographic profile of caregivers of patients living in institution

	Patients with dementia				
	mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
Number of caregivers	7	21	19	75	122
	N (%)	N (%)	N (%)	N (%)	N (%)
Sex					
Male	2 (28.6)	6 (28.6)	6 (31.6)	30 (40.0)	44 (36.1)
Female	5 (71.4)	15 (71.4)	13 (68.4)	45 (60.0)	78 (63.9)
Age					
mean (s.d.)	58.6 (7.3)	56.5 (10.6)	58.6 (8.7)	60.1 (11.0)	59.2 (10.4)
Relation to patient					
Wife/husband	0 (0.0)	0 (0.0)	0 (0.0)	11 (14.7)	11 (9.0)
Sister/brother	0 (0.0)	1 (4.8)	1 (5.3)	2 (2.7)	4 (3.3)
Daughter/son	5 (71.4)	14 (66.7)	10 (52.6)	40 (53.3)	69 (56.6)
Other	2 (28.6)	4 (19.0)	8 (42.1)	16 (21.3)	30 (24.5)
Missing data		2 (9.5)		6 (8.0)	8 (6.6)

s.d. : standard deviation.

Table 3
Number of patients with dependence for activities of daily living measured with the Katz scale

	Referent patients (no cognitive impairment) (n = 106)	Patients with CIND (n = 113)	Patients with dementia				
			mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
			(n = 83)	(n = 108)	(n = 62)	(n = 133)	(n = 386)
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Personal care	6 (5.7)	8 (7.1)	13 (15.7)	21 (19.4)	28 (45.2)	104 (78.2)	166 (43.0)
Clothing	6 (5.7)	8 (7.1)	13 (15.7)	22 (20.4)	30 (48.4)	105 (78.9)	170 (44.0)
Moving	1 (0.9)	3 (2.7)	3 (3.6)	11 (10.2)	9 (14.5)	60 (45.1)	83 (21.5)
Going to toilet	1 (0.9)	0	2 (2.4)	9 (8.3)	14 (22.6)	70 (52.6)	95 (24.6)
Contenance	0	1 (0.9)	6 (7.2)	12 (11.01)	18 (29.0)	78 (58.6)	114 (29.5)
Eating	0	0	1 (1.2)	2 (1.9)	7 (11.3)	46 (34.6)	56 (14.5)

CIND : cognitive impairment, no dementia.

SF-36

The PCS scores were comparable across the different cohorts for all caregivers, with means of 44.9, 45.0 and 45.3, respectively, for caregivers of referent, CIND and demented patients (Table 4). However, these mean values do not give an adequate representation of the differences observed by gender, age and cohabitation status. The difference between subjects < 65 years and those ≥ 65 years was 8.4 for caregivers of referent patients, 6.5 for caregivers of CIND patients and 4.8 for caregivers of demented patients. The large differences observed between cohabitant and non-cohabitant caregivers (10.2, 7.8 and 5.2, respectively, for caregivers of referent, CIND and demented patients) can be at least partly explained by the differences of age and relationship with the patient (Table 2). There was an important decrease for the MCS scores obtained by caregivers in relation to the impairment of the cognitive status of the patients provided

with care (referent patients : 51.3, CIND patients : 47.7, demented patients : 45.4), except for caregivers of severely demented patients (Table 4). A higher score for caregivers of patients with severe dementia than for caregivers of patients with moderate dementia was found for the four dimensions included in the mental component score : social functioning, emotional role, mental health and vitality (data not shown). It is noteworthy that the decrease of MCS scores existed in the majority of categories defined by gender, age and habitation status.

Depression

More caregivers of demented patients than caregivers of referent patients and CIND patients had signs of depression (42.5%, 32.6% and 31.3%) (Table 5). Among those with depression, caregivers of demented patients were more often with moderate or severe depression (22.3%) than those of

Table 4

Mean (standard deviation) PCS and MCS scores for caregivers of referent and demented patients living at home

	Referent patients (no cognitive impairment)	Patients with CIND	Patients with dementia				
			mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
<i>PCS</i>							
N	41	68	50	64	30	32	176
All caregivers	44.9 (11.9)	45.0 (9.9)	45.4 (11.8)	45.9 (10.9)	44.8 (11.7)	44.8 (12.3)	45.3 (11.6)
Males	44.6 (12.1)	43.6 (8.6)	45.1 (9.6)	44.1 (11.1)	50.3 (5.0)	45.4 (10.5)	45.6 (9.9)
Females	44.3 (12.0)	45.8 (10.4)	45.5 (13.3)	46.9 (10.8)	42.4 (13.1)	44.6 (13.1)	45.2 (12.4)
< 65 years	50.9 (8.7)	49.7 (8.5)	49.8 (12.1)	48.4 (8.9)	44.6 (14.0)	48.9 (11.3)	48.2 (11.1)
≥ 65 years	42.5 (12.1)	43.2 (9.8)	44.0 (11.5)	44.3 (1.9)	45.0 (10.3)	39.1 (11.5)	43.4 (11.5)
Cohabitant	43.1 (12.1)	44.1 (10.0)	43.3 (11.7)	45.3 (11.4)	44.1 (12.0)	42.9 (12.1)	44.0 (11.7)
Non cohabitant	53.3 (4.9)	51.9 (5.1)	54.2 (7.7)	47.9 (9.5)	49.9 (9.6)	47.8 (12.3)	49.2 (10.5)
<i>MCS</i>							
N	42	67	50	65	30	32	177
All caregivers	51.3 (9.2)	47.7 (11.0)	47.4 (11.3)	44.5 (12.8)	42.0 (12.8)	46.4 (11.3)	45.4 (12.1)
Males	52.2 (8.3)	50.8 (10.1)	46.7 (11.9)	46.4 (13.5)	44.3 (10.6)	47.8 (9.3)	46.5 (11.5)
Females	51.0 (9.7)	46.2 (11.2)	47.9 (11.0)	43.6 (12.5)	40.9 (13.8)	45.8 (12.1)	44.8 (12.4)
< 65 years	51.7 (7.4)	48.2 (8.4)	44.9 (14.7)	46.4 (13.5)	43.1 (13.3)	45.6 (12.1)	44.2 (12.6)
≥ 65 years	51.2 (9.8)	47.6 (11.9)	48.2 (10.2)	43.6 (12.5)	41.2 (12.8)	47.5 (10.2)	46.1 (11.7)
Cohabitant	51.9 (9.4)	47.6 (11.5)	47.7 (12.2)	42.7 (12.4)	41.0 (13.4)	47.8 (10.7)	45.7 (12.5)
Non cohabitant	47.4 (7.5)	48.7 (6.1)	46.2 (6.7)	45.7 (13.0)	48.8 (4.5)	44.2 (12.1)	44.4 (10.8)

CIND : cognitive impairment, no dementia.

PCS : SF-36 Physical Component Score.

MCS : SF-36 Mental Component Score.

Table 5

Number (%) of caregivers of patients living at home with depression, assessed by the short form Beck depression inventory, by cohabitation status

Severity of depression	Referent patients (no cognitive impairment)	Patients with CIND	Patients with dementia				
			mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
<i>All caregivers</i>							
none/minimal	29 (67.4)	44 (68.7)	36 (70.6)	39 (57.4)	13 (40.6)	20 (54.1)	108 (57.5)
mild	9 (20.9)	8 (12.5)	5 (9.8)	15 (22.0)	8 (25.0)	10 (27.0)	38 (20.2)
moderate	5 (11.6)	9 (14.1)	8 (5.3)	14 (20.6)	9 (28.1)	7 (18.9)	38 (20.2)
severe	0	3 (4.7)	2 (14.3)	0	2 (6.3)	0	4 (2.1)
<i>Cohabitant caregivers</i>							
none/minimal	24 (64.9)	37 (66.1)	27 (64.3)	28 (52.8)	11 (37.9)	18 (54.5)	84 (53.5)
mild	8 (21.6)	8 (14.3)	5 (11.9)	11 (20.8)	7 (24.1)	9 (27.3)	32 (20.4)
moderate	5 (13.5)	8 (14.3)	8 (19.0)	14 (26.4)	9 (31.0)	6 (18.2)	37 (23.6)
severe	0	3 (5.3)	2 (4.8)	0	2 (6.9)	0	4 (2.5)
<i>Non cohabitant caregivers</i>							
none/minimal	5 (83.3)	7 (87.5)	9 (100.0)	11 (73.3)	2 (66.7)	2 (50.0)	24 (77.4)
mild	1 (16.7)	0		4 (26.7)	1 (33.3)	1 (25.0)	6 (19.4)
moderate	0	1 (12.5)		0	0	1 (25.0)	1 (3.2)
severe	0	0		0	0	0	0

CIND : cognitive impairment, no dementia.

Table 6
Sense of Competence in caregivers of demented patients living at home

	Patients with dementia living at home				
	mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
Number of caregivers	53	71	32	37	193
<i>Satisfaction given by demented patient as recipient of care</i>					
Number of valid responses	43	66	28	30	167
Mean (s.d.)	5.2 (2.4)	5.2 (2.1)	5.3 (2.1)	5.4 (1.9)	5.2 (2.1)
<i>Self-satisfaction as caregiver</i>					
Number of valid responses	35	61	24	29	149
Mean (s.d.)	8.8 (2.4)	8.2 (2.8)	8.0 (3.2)	8.1 (2.7)	8.3 (2.7)
<i>Consequences for personal life</i>					
Number of valid responses	44	66	28	30	168
Mean (s.d.)	4.4 (2.8)	3.9 (2.4)	2.7 (2.6)	3.2 (2.1)	3.7 (2.6)
<i>Total score</i>					
Number of valid responses	44	66	28	30	168
Mean (s.d.)	18.0 (7.5)	17.1 (6.3)	15.4 (6.3)	17.0 (5.5)	17.1 (6.5)

s.d. : standard deviation.

referent (11.6%) or CIND patients (18.8%). These figures also increase with the severity of dementia, except for caregivers of patients with severe dementia. The prevalence and severity of depression were also higher in cohabitant than non-cohabitant caregivers, with prevalence figures of 46.5%, 35.1% and 33.9% for cohabitant caregivers of demented, referent and CIND patients. The respective figures were 22.6%, 16.7% and 12.5% for non-cohabitant caregivers.

Sense of Competence

For caregivers of patients living at home (Table 6), the mean score for the satisfaction given by demented patients as recipients of care was 5.2 for all caregivers and was not influenced by the severity of dementia. In contrast, the mean score for the criterion "self-satisfaction as caregiver" was 8.3, with an important decrease of the score with severity of patients' dementia (8.0 and 8.1, respectively, for caregivers of patients with moderate and severe dementia), especially in comparison with the score obtained for mild dementia (8.8). The severity of dementia had also important consequences on personal life (mean : 3.7), with a sharp decrease from "mild to moderate" dementia to "moderate" and "severe" dementia. Overall, a total score of 17.1 was found in caregivers of patients living at home. The highest score was found in caregivers of patients with mild dementia, and the lowest in caregivers of patients with moderate dementia (15.4). It is noteworthy that caregivers of patients with severe dementia had a total sense of competence score (17.0) which was comparable to that of patients with mild to moderate dementia.

Similar patterns were found for results obtained for caregivers of patients living in institution (Table 7), with an important decrease with the severity of dementia for two criteria : self-satisfaction as caregiver and consequences on personal life. In this case, however, caregivers of severely demented patients rated worse than those of patients with moderate dementia. A total score of 20.0 was found in caregivers of patients living in institution. This score was higher than that found in caregivers of patients living in the same home (17.0).

Discussion

The need to objectively measure QoL in chronic conditions such as dementia, in addition to the measurement of clinical outcomes, is now widely recognised as a tool to evaluate the severity and progress of diseases and compare benefits and risks associated with the available therapies (Anonymous, 1995 ; Fitzpatrick *et al.*, 1992 ; Walker *et al.*, 1998, Ware, 1993, Windblad *et al.*, 2000). QoL has also been used as an outcome measure for consequences of caring and for programmes to support caregivers of demented patients living at home. However, what constitutes QoL is a personal and individual question which lends itself to a philosophical rather than a scientific approach (Slevin *et al.*, 1988). For example, it has been shown that patients with a mild cognitive deficit tend to overestimate their functional abilities (Howard and Rockwood, 1995 ; Lawton, 1994), but that caregivers tend to underestimate the abilities of patients they are caring for (Seltzer and Buswell, 1994).

Table 7
Sense of Competence in caregivers of demented patients living in institution

	Patients with dementia living at home				
	mild dementia	mild to moderate dementia	moderate dementia	severe dementia	all demented patients
Number of caregivers	6	19	16	65	106
<i>Satisfaction given by demented patient as recipient of care</i>					
Number of valid responses	6	17	15	52	90
Mean (s.d.)	5.7 (1.9)	5.7 (2.0)	6.1 (1.3)	6.0 (1.5)	5.9 (1.6)
<i>Self satisfaction as caregiver</i>					
Number of valid responses	6	17	16	43	82
Mean (s.d.)	10.0 (1.7)	9.2 (2.6)	8.6 (3.5)	8.4 (2.6)	8.7 (2.7)
<i>Consequences for personal life</i>					
Number of valid responses	6	18	18	49	89
Mean (s.d.)	6.2 (2.6)	5.7 (2.0)	6.0 (1.5)	4.8 (2.7)	5.3 (2.5)
<i>Total score</i>					
Number of valid responses	6	18	16	52	92
Mean (s.d.)	21.8 (6.0)	20.7 (4.5)	20.5 (5.3)	19.3 (5.1)	20.0 (5.1)

s.d. : standard deviation.

Poor agreement was found between patient and proxy reports of QoL in Alzheimer's disease (Albert *et al.*, 1996, Novella *et al.*, 2001), even if spouses and nurses agreed more closely with the patient than other proxies (Novella *et al.*, 2001).

An attempt was made in this study to objectively measure both generic and specific dimensions of QoL in both patients and caregivers. For patients, the use of the COOP/WONCA chart to evaluate global QoL was not successful, as 25% of patients with moderate dementia and 75% of patients with severe dementia were not able to fully answer the questionnaire. Difficulties in measuring subjective components of QoL in demented patients were also observed in a study using the Duke Health questionnaire where help from the interviewer was necessary in 79% of cases (Novella *et al.*, 2001). Given this difficulty, readily observable behaviours are often used as a basis for assessing the QoL of demented patients (Albert *et al.*, 1996), and activities of daily living, using the Katz and the Lawton scales, were assessed in this study. These scales demonstrated a clear association between an impairment in these dimensions, cognitive impairment and severity of dementia. In severely demented patients, complete functional dependence culminated in 78.9% for clothing and 78.2% for personal care, with comparative figures of 5.7% and 7.1%, respectively, for referent and CIND patients. Similarly, the mean IADL score on the Lawton scale decreased from 5.6 in referent patients to 5.0 for CIND patients and 2.0 for demented ones. These findings are in agreement with those of Barberger-Gateau *et al.* (1992) and De Lepeleire *et al.* (1998) which showed a good correlation between ADL-IADL disturbances and cognitive

impairment, especially, among IADL items, telephone use, use of means of transportation, responsibility for medication intake, and handling of finances. The results of this study also show that scores of QoL for CIND patients were intermediate between those found for referent patients and those for mildly demented patients, although they were generally closer to those for referent patients than those for mildly demented patients.

Caregivers play a central role in the management of dementia, and much research has been made in the last years on determinants of ability to care for the patient and programmes to foster this ability. In this study, we used two generic (COOP/WONCA and SF-36) and two specific (Beck depression inventory and SCQ) measures to assess the consequences of patients cognitive status and severity of dementia on the QoL of caregivers. A consistent feature of results obtained with these questionnaires was a generally better QoL for caregivers living with patients with severe dementia than for those living with patients with moderate dementia, especially for the SF-36 MCS, the percentage of patients with depression, and the "Self satisfaction as caregiver" and "Consequences for personal life" dimensions of the SCQ. For the SF-36, this pattern was found for the four dimensions included in the MCS : social functioning, emotional role, mental health and vitality. No explanation for this constant difference could be found in our data. It is possible that, due to the progression of the disease and the lack of patients recognition, caregivers living with severely demented patients become less concerned by their role as family member, giving more prominence to the quality of the caregiving than to the emotional aspects associated to their task.

Differences of socio-economic status between caregivers could also explain part of the differences of QoL scores. However, the socio-economic status of caregivers was not measured in his study and its effect can not be assessed.

In the general U.S. population which is used as the reference for the computation of standardized scores, the mean MCS score was 52.7 and 50.4 in people aged 65-74 and ≥ 75 years, respectively (Ware *et al.*, 1994). In this study, mean MCS scores of 51.3, 47.7 and 45.4 for caregivers of referent, CIND and demented patients were found, reflecting the impact of cognitive disorders and dementia on the mental health of caregivers. The PCS scores did not show the same association with patients cognitive status and severity of dementia found for MCS scores. A comparable result was found by Bell *et al.* (2001), who reported that only MCS scores varied across both disease stage and setting. Thus, the SF-36 MCS appears to be a sensitive measure of the impact of cognitive impairment and dementia on the QoL of caregivers.

Depression has been reported to occur frequently among caregivers of patients with dementia, and this study brings additional evidence by showing that the prevalence of depression increases with the severity of dementia (59.4% in caregivers of patients with moderate dementia *versus* 29.4% in those of patients with mild dementia, 42.5% overall). Moreover, the prevalence of depression is much higher in cohabitant caregivers of referent (35.1%), CIND (33.9%) and demented (46.5%) patients than in non-cohabitant caregivers (16.7%, 12.5% and 22.6%, respectively). These results are in good agreement with those reported in other studies. In a study on 700 people aged ≥ 65 living in London, Livingston *et al.* (1996), reported that 47% of women caregivers of people with dementia suffered from depression while the prevalence of depression in caregivers overall or in coresidents ranged from 11% to 15%. In a study on 44 caregivers of spouses with a diagnosis of Alzheimer's disease, Fiore *et al.* (1983) reported that 43% met the criteria for a depressive disorder. An association between severity of dementia and depression was also found by Ballard *et al.* (1995) and Karlawish *et al.* (2001). According to a literature review by Schulz *et al.* (1990), most studies indicate that caregivers of Alzheimer's patients but also of Parkinson's disease patients and caregivers of physically impaired patients show elevated rates of clinical depression.

The concept of Sense of Competence was used in this study to denote the caregiver's feeling of being capable of caring for the demented person. It includes three dimensions which were shown to have a high degree of correspondence with ratings made by a panel of experts. It was also found sensitive in a randomised controlled study aiming at reducing problems met by caregivers (Vernooij-

Dassen and Persoon, 1996). In this study, two dimensions (satisfaction with one's own performance as caregiver and consequences of involvement in care for the personal life of the caregiver) were sensitive to the severity of dementia, both for patients living at home and for those living in institution. The original studies made with the SCQ (Vernooij-Dassen, 1993) have shown that differences for these dimensions are influenced by the patient's neurological function and apathy and by the emotional support received by the caregiver. Similar results were found in a study based on Zarit's Burden Interview (Leinonen *et al.*, 2001), which showed that caregiving spouses of demented patients with psychiatric symptoms were more burdened than those of demented patients with mild to moderate memory impairment. In this study, however, like for the other measures, caregivers of patients with moderate dementia rated worse than those of patients with severe dementia. For caregivers of patients living in institution, the SCQ was administered by telephone, and, therefore, its results cannot be directly compared to those for caregivers of patients living at home. The SCQ also showed a decline with the severity of dementia, although it was at a higher level than for caregivers of patients living at home.

In summary, our study has shown that the functional status of aged people is markedly impaired by dementia. Activities of daily living are particularly affected, with a much higher proportion of demented patients affected than CIND and referent patients, even in patients with mild dementia. This impairment was also reflected in the assessment of instrumental activities of daily living, which evaluates a person's ability to cope with his/her environment in terms of adaptative tasks. Lower scores (and therefore lower capability to cope with these tasks) were found in demented than in CIND and referent patients.

A more extensive assessment of health-related QoL could be performed in caregivers of aged patients. Caregivers of moderately and severely demented patients in particular show marked impairments of their QoL. Emotional problems, problems in mental health and social activities are apparent from the SF36 questionnaire, the COOP/WONCA charts and the short form Beck depression inventory. Moreover, the scores of caregivers of CIND patients were intermediate between those obtained by caregivers of referent patients and caregivers of patients with mild dementia. These data show that CIND patients and their caregivers represent a group of people who need to be distinguished from patients (and their caregivers) without cognitive disorders.

On the basis of results of a questionnaire assessing the psychological burden of caring, caregivers of demented patients expressed the feeling that their self-satisfaction as caregiver and the consequences

for their personal life worsened with increasing cognitive impairment and increasing severity of dementia in the patients. From psychological studies, these dimensions have been shown to be related to the patient's agitation, apathy and emotional support. Therefore, our data provide additional evidence for the need to support caregivers of demented patients living at home. Improving the patient's cognitive status and providing assistance to caregivers would be complementary ways of action.

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