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Original Study

Risk Factors of Caregiver Burden Evolution, for Patients With Subjective Cognitive Decline or Neurocognitive Disorders: A Longitudinal Analysis

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A B S T R A C T

Background/Objectives: The identification of factors used to predict caregiver burden may help preventive care. This study aimed to assess the relationship between evolution of patients with subjective cognitive decline (SCD) or progressive neurocognitive disorder (NCD) and evolution of caregiver burden.
Design: Observational, longitudinal study.
Setting: The study was conducted in the Clinical and Research Memory Center of the University Hospital of Lyon (France), between the November 1, 2011 and the June 30, 2014, with a maximum follow-up of 30 months.
Participants: The study population included outpatients with SCD or NCD at all stages, and their informal caregiver.
Measurements: The caregiver burden was assessed during 2 visits of the patients and their caregiver, with the short version of the Zarit Burden Inventory (ZBI). Functional, cognitive performance, and behavioral and psychological symptoms were measured twice, concomitantly with the ZBI, using the Instrumental Activities of Daily Living (IADL) scale, the Mini-Mental State Examination (MMSE), and the Neuropsychiatric Inventory (NPI), respectively. Etiology and stage of the cognitive impairment were collected.
Results: The population study included 222 patients (mean age at inclusion: 80 years old, 62.9% females), with an average follow-up 12.6 ± 6 months. Proportion of patients with major NCD at the second visit (62.2%) increased compared with inclusion (50.0%). MMSE and IADL decreased between the 2 visits ($P < .001$), whereas ZBI increased (mean ZBI: 3.2 ± 2 at baseline, mean ZBI: 3.8 ± 2 at follow-up, $P < .001$). In unadjusted analyses, ZBI tended to be higher for patients whose MMSE decreased of at least 3 points between the visits. ZBI increased over time when IADL decreased (P value for within-patient effect <.001), while it remained stable when the IADL increased. ZBI increased when NPI increased. After mutual adjustment for change of MMSE, IADL, NPI, and etiologies, increase of ZBI over time remained significant when MMSE decreased at least 3 points between baseline and follow-up, when IADL decreased, and when NPI increased of at least 4 points.
Conclusions: In a study population of patients with SCD or NCD at all stages, concomitant decrease of cognitive performance, increase of functional impairment, and increase neuropsychiatric symptoms over time were independently associated with increased caregiver burden. The identification of risk factors associated with an increased caregiver burden over time may allow a better evaluation of the impact of specific interventions on cognitive, behavioral, and functional dimensions of NCD on caregivers.
Trial registration: ClinicalTrials.gov NCT02825732.

The authors declare no conflicts of interest.

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The presence of an informal caregiver contributes to home support for patients with progressive neurocognitive disorders (NCDs) and may delay nursing home transfer.[1] However, informal caregivers are frequently exposed to health comorbidities, especially affective disorders.[2] In addition, the large part of cost of care for patients with NCD is supported by informal caregivers. According to a previous study conducted in the United States, the annual cost of informal care of patients with dementia was $18,385 per patient, 34% of which was for caregiving time and 66% for caregiver's loss of earnings.[3] In a study conducted in the North of Europe, informal care cost, estimated by the caregiver time spent with patient, was on average $20,285 per patient with Alzheimer disease (AD), although authors cautioned that the costs vary across countries.[4]

Previous cross-sectional studies have shown that caregiver burden increases with the degree of severity of symptoms related to cognitive impairment of their relatives, as well as with the severity of patients' comorbidities.[5–9] Cognitive and functional impairment, as well as behavioral disorders, were shown to be associated with higher caregiver burden independent of cognitive impairment etiology.[7] Yet, longitudinal studies describing the evolution of caregiver burden and the risk factors associated with this evolution remain scarce and focused on specific etiologies such as AD or on patients with dementia.[10–13] In a previous study conducted in Spain and published in 2014, the authors showed that caregiver burden, measured with the Zarit Burden Interview (ZBI), increased slightly during the 3 years of follow-up and that neuropsychiatric symptoms and functional impairment of patients with probable AD were associated with increased caregiver burden.[10] In the same country, another study found that caregiver burden improved slightly during 12 months of follow-up, for caregivers of patients with moderate to severe AD.[13] In this study, behavioral impairment was the factor the most related to caregiver burden compared with functional or cognitive decline.

In a previous cohort study conducted in Australia among patients with dementia, the caregiver burden increased at 36 months of follow-up and behavioral disorders, rapid functional decline, and use antipsychotics and antidepressants were found as significant predictors of increased caregiver burden.[11] In another study conducted in Germany, the caregiver burden measured with the Caregiver Burden Interview remained stable over 2 years of follow-up, whereas the severity of the symptoms (functional impairment and behavioral disturbances) in patients with dementia increased over the same period of observation.[12] Nevertheless, no previous longitudinal study included patients with subjective cognitive decline (SCD), defined as the presence of a subjective cognitive complaint with unimpaired performance on the objective neuropsychological evaluation.[14]

In this context, it is interesting to investigate this objective among patients with SCD or at various stages of NCD (as measured by The Diagnostic and Statistical Manual of Mental Disorders, 5th ed. [DSM-V] and whatever the etiologies) who are followed at a memory center. This improves the understanding of the conditions and risk factors linked to caregiver burden and make it possible to plan specific interventions aimed at supporting caregivers.[15]

This study goals were to assess the relationship between the evolution of symptoms of patients with cognitive complaint, measured twice successively, at minor and major stages of NCD, as well as among patients with SCD, and the evolution of caregiver burden, assessed with the short version of the ZBI, in a cohort study conducted in a memory center.

Methods

Study Design, Setting, and Follow-Up

This observational and monocenter study was based on an outpatient cohort, extracted from a patient medical record database at the Clinical and Research Memory Centre of Lyon (Charpennes Hospital, University Hospital of Lyon, France). Repeated measurements were collected at 2 successive visits of patients, in routine care, at the memory center between the November 1, 2011 and June 30, 2014.

Study Population

The study population included the dyad of patient-caregiver for patients who have undergone a memory visit with a neurologist or a geriatrician. Patients visited the memory center after a cognitive complaint, either expressed by themselves or by one of their relatives. Patient characteristics visiting the memory center have been described previously in a cross-sectional study.[6,7] Inclusion criteria were patients with a cognitive complaint, either expressed by the patient or one of their relatives, at any stage of disease (SCD, mild or major NCD), patients living in the community, and having an informal caregiver who completed the questionnaire to assess the caregiver burden at 2 successive visits.

Written information regarding the collection of individual data was provided to the patient and caregivers. Authorization for handling personal data has been granted by the French Data Protection Authority (CNIL: Commission Nationale de l'Informatique et Libertés): June 08, 2010, number of registration: 10–18. The study has been registered in the register ClinicalTrials.gov with the number NCT02825732.

Data Collection

All patient and caregiver data were reported in an electronic case report form, using the software Cristalnet, developed by the Centre Régional Informatique Hospitalière des Alpes and the computer and software service of the University Hospital of Grenoble, Grenoble, France. The data were entered in the electronic case report form by trained medical and paramedical staff, at every patient visit. Follow-up visit was planned within the usual monitoring time frame of patients at the memory center, typically 12 months after the first consultation. The delay between the consultations may vary according to the need of care and management of the patient's health.

Primary Outcome: Caregiver Burden Change

The caregiver burden change was assessed using 2 repeated measures of the validated short version of the ZBI.[16,17] The short version of ZBI score ranged from 0 (no burden) to 7 (higher burden). This score is corresponding to the sum of the answers to 7 questions to which the caregivers answered "never" (0 point), "sometimes" (0.5 point), or "nearly always" (1 point). As described previously, the answers were first self-reported by the informal caregiver in a questionnaire sent to their home before the patient's consultation at the memory center.[6,7] The questionnaires were then verified by a nurse in an interview with the caregiver during the patient visit.

Patient's Characteristics Collected at Baseline

The following patient's characteristics were collected at baseline during the routine care visits: age, sex, the current living situation of the patient including living at home with a spouse, at home with relatives, alone at home with relatives in the neighborhood, alone at home without relatives in the neighborhood, or unspecified other living situation. The relationship between the patients and their caregivers was recorded as (1) spouse, (2) child, stepchild, or grandchild, (3) brother, sister, niece or nephew, or (4) other unspecified caregiver.