

## Caregiver time use in ALS

**Abstract**—The authors evaluated the caregiver time for 70 patients with ALS. The mean number of caregivers per patient was 2.0 (SD 1.3). Caregiver time increased with worsening of disability ( $p = 0.0001$ ). The most time-consuming duties were housekeeping, feeding, and toileting. With worsening of patients' disability, families relied increasingly on paid caregivers. Caregiver time is a hidden cost of ALS care and is a major burden for caregivers.

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Time taken for caregiving is a major problem in ALS.<sup>1</sup> However, in contrast to other chronic neurologic disorders, such as Alzheimer disease (AD)<sup>2</sup> or stroke,<sup>3</sup> the amount and characteristics of caregiver time has never been formally assessed in ALS. We therefore assessed the use of time by ALS caregivers in relation to the severity of disability and the use of life-supporting procedures.

**Methods.** We studied 70 consecutive patients affected by probable, probable laboratory-supported, and definite ALS, according to revised El Escorial criteria, who were attending the Turin ALS Center or were visited at their home by one of the authors during a 2-month period (February to March 2005). No patient declined participation in the study. All caregivers, professional (paid) or voluntary (unpaid), were interviewed. Caregiver time allocation was evaluated using the Caregiver Activity Time Survey (CATS),<sup>4</sup> which analytically measures the use of time in nine areas: feeding, toileting, bathing, dressing, administering medications, supervision, housekeeping, transportation, and other tasks. The caregivers were asked to record in a diary the total time (hours and minutes) spent for caregiving in a typical 24-hour period for each task. Disability of patients was evaluated with the ALS Functional Rating Scale (ALS-FRS). The Italian National Health System pays for tracheostomy and enteral nutrition. In addition, patients with severe disability receive 400 euros (\$450) per month to help pay for professional caregivers.

Statistical analysis was performed with multiple regression analysis. A  $p$  value less than 0.01 was considered significant.

**Results.** The 70 patients (28 women, 42 men) had a mean age of 61.3 years (SD 10.6) with a mean disease duration of 48.8 months (SD 38.3; median 26 months, range 4 to 360 months). Twelve patients received enteral nutrition via percutaneous endoscopic gastrostomy/radiologically inserted gastrostomy, 10 used noninvasive positive-pressure ventilation (NIPPV), and 4 used mechanical ventilation with tracheostomy. The mean number of caregivers per patient was 2.0 (SD 1.3; range 1 to 8), including 121 voluntary caregivers (55 spouses, 51 sons/

daughters, 6 parents, 9 other relatives) and 18 paid caregivers. The mean time spent in caregiving was 570 minutes each day (SD 512; range 15 to 3,051). Caregiver time increased with increased disability score ( $r = -0.48$ ;  $p = 0.0001$ ) (table 1). The mean number of caregivers for each patient also increased with the worsening of disability score ( $r = -0.65$ ;  $p = 0.0001$ ) (table 1), as did both the mean number of paid caregivers ( $r = -0.34$ ;  $p = 0.004$ ), and the mean caregiver time by paid caregivers ( $r = -0.35$ ;  $p = 0.003$ ) increased (table 1).

Considering caregiving time for each area of the CATS according to severity of ALS disability (table 2), the most time-consuming domain was housekeeping (158.1 minutes), followed by feeding (97.6 minutes), and toileting (83.5 minutes). A progressive increase of caregiving time with the increase of disability was found for toileting, bathing, dressing, administering medications, and, to a lesser extent, feeding, whereas the other areas showed erratic (dressing, other) or no relevant modifications (supervision, transportation). A correlation was found between total caregiver time and impairment of legs ( $r = -0.46$ ;  $p = 0.0001$ ) and arms or hands ( $r = -0.41$ ,  $p = 0.0004$ ), but not with bulbar ( $r = -0.23$ ;  $p = 0.06$ ) or respiratory impairment ( $r = -0.21$ ;  $p = 0.08$ ). However, when considering only patients without enteral nutrition, there was a correlation between the feeding item of the CATS and the bulbar score of the ALS-FRS ( $r = -0.74$ ;  $p = 0.0001$ ), but not total caregiver time. Moreover, the amount of caregiver time was not significantly related to enteral nutrition, NIPPV, or tracheostomy.

In multivariate analysis, the only factors independently related to caregiver time were leg impairment ( $p = 0.001$ ) and age ( $p = 0.01$ ).

**Discussion.** The issue of caregiver time has been analyzed in AD, where the amount of caregiver time increases sharply as cognitive impairment worsens.<sup>5,6</sup> Likewise, in elderly people with stroke, voluntary caregiver time is related to the severity of clinical symptoms.<sup>3</sup>

We have found that caregiver time is highly related to overall disability, and ranged from a mean of 5 hours for patients with a mild disability (ALS-FRS score  $> 30$ ) to a mean of 15 hours for those with severe impairment (ALS-FRS score  $\leq 10$ ). With increased disability, there was also a significant increase of the number of caregivers involved in each

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**Table 1** Mean and range of caregiving time according to ALS-FRS score

| ALS-FRS | No. of cases | Mean no. of caregivers (SD) | Mean caregiving time (SD) | Range     | Mean no. of paid caregivers (SD) | Mean caregiving time, paid caregivers (SD) |
|---------|--------------|-----------------------------|---------------------------|-----------|----------------------------------|--|
| 31–40   | 23           | 1.5 (0.8)                   | 313.6 (235.7)             | 15–780    | 0.1 (0.3)                        | 26.3 (89.0)                                |
| 21–30   | 22           | 2.0 (1.2)                   | 626.7 (460.1)             | 75–1,510  | 0.2 (0.5)                        | 72.3 (168.9)                               |
| 11–20   | 15           | 2.2 (1.9)                   | 848.7 (732.2)             | 240–3,051 | 0.4 (0.8)                        | 151.9 (369.7)                              |
| 1–10    | 10           | 2.5 (1.2)                   | 899.6 (435.6)             | 540–1,880 | 0.6 (0.7)                        | 271.9 (340.6)                              |

ALS-FRS = ALS Functional Rating Scale.

**Table 2** Mean caregiving time (minutes) for each domain of the CATS for different levels of ALS-FRS

| CATS domains              | ALS-FRS score |       |       |       | Overall |
|---------------------------|---------------|-------|-------|-------|---------|
|                           | 0–10          | 11–20 | 21–30 | 31–40 |         |
| Feeding                   | 125.6         | 195.7 | 84.1  | 43.3  | 97.6    |
| Toileting                 | 240           | 93.4  | 88    | 20.2  | 83.5    |
| Bathing                   | 82.5          | 23.7  | 31.7  | 4.6   | 26.4    |
| Dressing                  | 85            | 34.2  | 58.1  | 17.8  | 42.5    |
| Administering medications | 87.5          | 22    | 35.5  | 17.2  | 33      |
| Supervision               | 8.8           | 40.4  | 96.8  | 17.9  | 46.3    |
| Housekeeping              | 195           | 188.6 | 141.2 | 142.8 | 158.1   |
| Transportation            | 11.9          | 43.6  | 42.6  | 30    | 34.6    |
| Other                     | 63.3          | 250   | 65.7  | 21.9  | 83.3    |

CATS = Caregiver Activity Time Survey; ALS-FRS = ALS Functional Rating Scale.

case. Loss of ability to stand and to walk had a profound impact on the need for care. In contrast, enteral nutrition, NIPPV, and even tracheostomy seemed to be only marginally related to caregiver time.

In another study,<sup>1</sup> we found that time allocation affected the perceived quality of life and perceived burden of ALS caregivers, which was mostly related to “personal and social restrictions”<sup>7</sup> or to “time-dependence burden” and “developmental burden” (which is interpreted as the feeling of the person to be out of time with respect to his or her peers).<sup>1</sup> Moreover, we have found that the amount of caregivers’ “time-dependence burden” significantly increased with the increase of patients’ disability.<sup>1</sup> Finally, a prospective study has observed that caregivers’ burden increased with the worsening of patient symptoms during a 6-month interval (A. Gauthier, unpublished data). As ALS progresses, the patient becomes more dependent on caregivers for everyday tasks; therefore, as demonstrated in the current study, the related caregiver time increases progressively, and so does the time burden on caregivers. However, it remains unclear whether the presence of paid caregivers really decreases the subjective burden of the

main caregiver.<sup>1</sup> With the worsening of patients’ disability, the families increasingly relied on paid

caregivers: for patients with a mild disability (ALS-FRS > 30), only 8% of caregiver time was performed by paid caregivers, a percentage that increased up to 30% for patients with a severe disability (ALS-FRS ≤ 10).

According to our findings, the amount of time that caregivers, both voluntary and paid, have to allocate to ALS patient care is comparable with caregiver time in AD,<sup>2</sup> and much higher than the estimated caregiver time for stroke.<sup>3</sup> Caregiver time is, therefore, at least for voluntary caregivers, a hidden economic cost, affecting their income by denying other occupational possibilities and quality of life. Using the median home health aid wage of \$8.92/hour in the United States, November 2004,<sup>8</sup> the annual caregiving costs would range from \$17,000 (for patients with mild disability) to \$48,800 (for patients with severe disability) per patient. With an estimated ALS prevalence of 8/100,000 population, the total annual cost of ALS caregiving in the United States would be not less than \$0.7 billion. This total cost is approximately 10% of the annual cost estimated for stroke-related voluntary caregiving,<sup>3</sup> even though the prevalence of ALS is only 2% of that of stroke.

The highly significant correlation between caregiver time and severity of disability warrant inclusion of this measure in ALS clinical trials, at least as a secondary endpoint, as in studies on AD.<sup>9</sup> The quantification of the actual needs in term of caregiver time in ALS could contribute to better comprehensive care of patients with ALS.<sup>10</sup>

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## NeuroImages

### Hypergraphia and the diagnosis of psychogenic attacks

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A 40-year-old woman was seen for a 2-year history of unusual spells of limp loss of consciousness without abnormal movements, lasting 2 to 10 minutes. There was no warning, no

incontinence, and no injury. The frequency was three to four times a week. Neurologic examination was normal. Past medical history and review of systems (figure), among other features, suggested a diagnosis of psychogenic episodes,<sup>1,2</sup> which was confirmed by EEG-video monitoring. Such hypergraphia is a helpful sign where both amount and content (fashionable diagnoses) are important, and may be specific for somatization,<sup>2</sup> though it may be associated with temporal lobe dysfunction.

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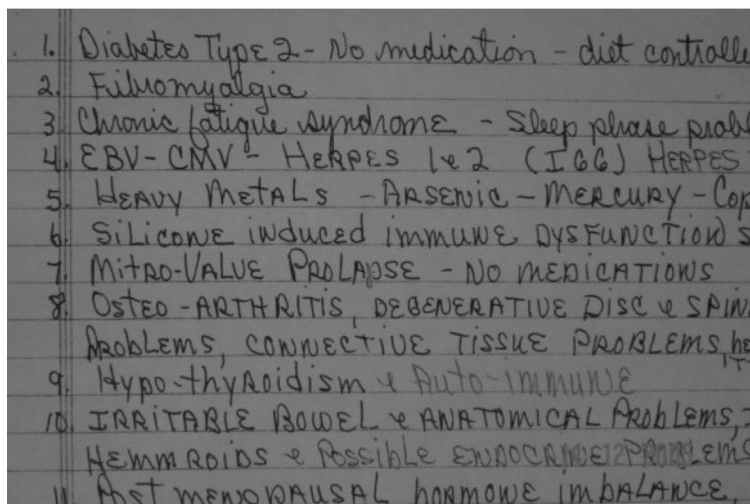
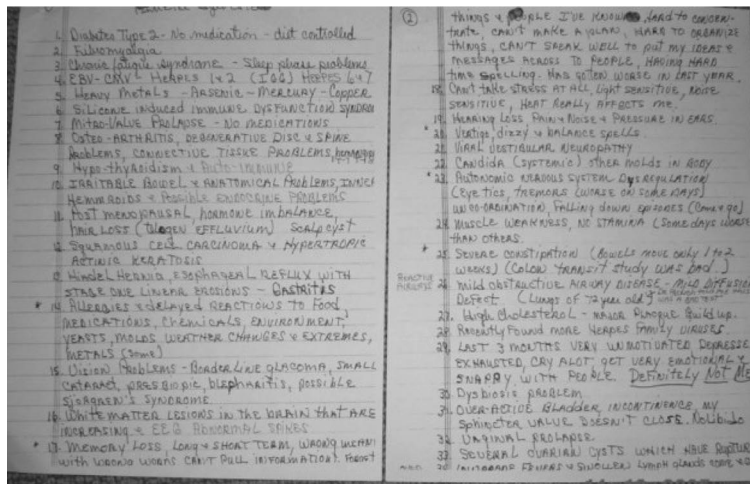


Figure. Past medical history and review of systems as written and provided by the patient. This type of florid list (hypergraphia) suggests somatization and predicts a diagnosis of psychogenic nonepileptic episodes.<sup>1,2</sup>

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