

ORIGINAL ARTICLE

Burden assessment in caregivers of patients with home artificial nutrition: a need and a challenge

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BACKGROUND/OBJECTIVES: Caregiving can be a stressful task with severe consequences on caregivers' health. Our aim was to evaluate the profile and the burden of caregivers of patients with home artificial nutrition (HAN) in our area.

SUBJECTS/METHODS: We conducted a prospective observational study of patients who had started HAN over a period of a year ($n = 573$) and their home caregivers ($n = 103$). Epidemiological characteristics of the patients and the type of HAN were registered. Caregivers' profile data (gender, age and degree of kinship) and Zarit Burden Assessments were recorded.

RESULTS: Care recipients had a median age of 79.0 (IQR 87) years, neurological and oncological diseases in 50% and a high rate of mobility limitations (80%). Oral supplements with high-calorie formulas were predominant (60%). The usual caregiver profile was a patient's daughter with a mean age of 53.1 (s.d. 13.4) years acting as the primary caregiver. Burden was absent in 49.5%, light in 18.4% and intense in 32% of caregivers. Intense burden was more frequent in oral over enteral nutrition (42% versus 22.6%; $P = 0.036$). Supplementary nutrition was also associated with higher caregiver burden scores compared with complete diets. In patients with functional limitations, a tendency toward a slightly higher burden was observed. No differences in caregiver burden were detected according to other patient or caregiver characteristics.

CONCLUSIONS: HAN type appears to be a factor influencing caregiver burden and therefore, evaluation of caregiver burden should be part of HAN programs.

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INTRODUCTION

Malnutrition, particularly disease-related malnutrition, is a serious public health problem because of its high prevalence, severe consequences and socioeconomic implications. Many studies have reported a clear association between malnutrition and hospitalization in various countries, including Spain.^{1–4} However, disease-related malnutrition also affects outpatients or those institutionalized in geriatric centers, especially certain groups such as cancer patients or the elderly. Consequently, a Spanish systematic review that included the most important studies on malnutrition in the elderly found a malnutrition prevalence rate ranging between 16.6 and 47.3%, depending on the diagnostic method used.⁵

Over the last decades, several strategies have been implemented to fight malnutrition. One of the most important techniques is home artificial nutrition (HAN), which has become a routine form of care in most developed countries, resulting in cost savings, proximity to family, optimization of normal social and professional life and improved quality of life.⁶ However, in many cases HAN administration requires the help of a caregiver.

Caregivers are defined as relatives or professionals who are in charge of dependent patients, helping them with basic activities of daily life. Informal caregivers, who do not receive financial remuneration, are an indispensable element in caring for dependent patients and for health care institutions.⁷ The informal

caregiver sometimes has to renounce part of his/her own life and suffer significant physical, emotional and economic consequences as a result of this important but demanding task. Some of these consequences include neglect of one's own health and a sense of loss of social life; deterioration of familial relationships; feelings of manipulation, guilt, or anger; anxiety or frustration related to the lack of training or knowledge in the care of dependent patients (medication, food and so on); isolation and refusal to seek help; and economic disempowerment due to a reduced chance of getting a job or the need to reduce their work hours.⁸

All this can lead to the appearance of burden syndrome, which is defined as the impact that a caregiver perceives on his/her emotional life, physical health, social life and financial situation as a result of his/her activity.⁹

Caregivers who suffer from this syndrome may be at increased risk of comorbidities, the most frequent being fatigue, sleep disturbances, gastrointestinal disorders, heart or blood pressure problems, bone and joint pain, anorexia, weight loss or loss of strength, skin diseases and allergies.^{10–13} Some of these symptoms, such as fatigue, may worsen as the relative's condition deteriorates. Besides being more susceptible to disease, the caregiver has less time for social activities, holiday or travel. This causes a high percentage of loneliness and isolation, as well as difficulties in maintaining relationships.⁸ All these changes influence one's ability to act as a caregiver. Thus, both the patient's and the caregiver's welfare are closely related; the higher

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the caregiver stress, the lower the quality of care. The significance of burden is such that it constitutes an independent risk factor for mortality in elderly caregivers.¹⁴

Despite the serious consequences of caregiver burden, there have been few studies in the field of HAN. Our aim was to evaluate the profile and burden of the caregivers of patients receiving nutritional support at home in Santiago de Compostela (Spain).

SUBJECTS AND METHODS

This prospective observational study included all patients who started HAN prescribed by the Department of Endocrinology and Nutrition of the Complejo Hospitalario Universitario de Santiago de Compostela in the period from 15 October 2009 to 14 October 2010. The recruitment process benefited from the fact that in our region (Galicia, Spain), the dispensation of HAN is centralized in hospital pharmacy departments. So, by collating the records of the Nutrition Unit and the Hospital Pharmacy Department, we avoided losing patients with HAN initiated during the study period. Patients with HAN prescribed and monitored by other hospital services were excluded because of the difficulties with proper data collection.

Baseline characteristics of the patients were registered at the first visit, including epidemiological, functional and nutritional data. They could come to the Nutrition Unit either after a hospital discharge or as outpatients. Nutritional assessment included anthropometry, laboratory tests and estimation of nutritional requirements. Nutritional classification of patients followed SENPE (Spanish Society of Enteral and Parenteral Nutrition) and SEDOM (Spanish Society of Medical Documentation) definitions.¹⁵ The type and administration route of HAN were also described. When HAN provided < 1000 kcal/day was considered supplementary nutrition, whereas when it provided \geq 1000 kcal/day was defined as complete nutrition.

The home caregivers of the patients were interviewed between the first and second week after initiating nutritional support therapy, considering that the HAN duration used to be short in an important subgroup of patients. An early evaluation allowed us to perform the interview at the same time across the sample and also provided very interesting information at the beginning, when the caregivers may have more questions and doubts about how to manage the therapy by themselves. Caregivers who did not help patients with HAN management were excluded. When nutritional support was initiated during hospital admission, ward nurses were responsible for handling the therapy. This fact avoided caregivers' contact with HAN (which could affect the caregiver's burden at home) until the day of discharge, when nutrition education was performed.

The profile data of the home caregivers included were recorded (gender, age and relationship with the patient), and burden was evaluated with the Zarit Interview. The Zarit Interview quantitatively assesses the subjective experience of caregiver burden. It consists of 22 items, each with 5 possible answers (never, rarely, sometimes, quite frequently or nearly always). In the original scale, each item is scored from 0 to 4 points, so the total score ranges between 0 and 88 points. However, the validation study in Spanish valued each item between 1 and 5 points, and thus, the total score could range between 22 and 110 points.¹⁶ Higher scores on the test are related to higher levels of burden. The Spanish system also established levels of burden. A result between 22 and 46 points correlates with the absence of burden, between 47 and 55 with light burden and greater than 56 points with intense burden.¹⁷

One of the 22 items on the Zarit Interview specifically assesses the doubts caregivers may have in caring for their relatives. This was used to investigate whether the caregiver had insecurities about HAN management.

Statistical analysis

Statistical analysis was performed with SPSS 19.0 (SPSS Inc., Chicago, IL, USA). The normal distribution of quantitative variables was examined by the Kolmogorov–Smirnov test. Variables matching normal distribution were presented as mean and s.d. and those without normal distribution as median and IQR. Quantitative variables were compared with *t*-test and Mann–Whitney test for normally and non-normally distributed data, respectively. Categorical variables were expressed as percentages and compared using a χ^2 test. A *P*-value lower than 0.05 was considered statistically significant.

Ethical issues

The study was conducted in accordance with the standards of good clinical practice and according to the ethical principles grounded in the Declaration of Helsinki in its latest update.

The Ethics and Clinical Research Committee of Lugo-Santiago (Spain) approved the study protocol, and both patient and caregiver anonymity was preserved. Informed consent was obtained from all included subjects.

RESULTS

During the study period, 788 patients started home nutritional support in the health area of Santiago de Compostela. However, only 573 patients were finally included in the study. The main reasons for exclusion were lack of prospective data, patients with HAN prescribed and monitored by other hospital services and patients with HAN prescribed by the Endocrinology and Nutrition Department who were not captured in the recruitment period (losses of the study; Figure 1).

Baseline characteristics of patients

Of the patients included in the registry, 59.7% were women with a median age of 79 (IQR 87) years, with a percentage of patients over 65 years of 78.6%. We found high levels of comorbidity (51.7% neurological diseases, 32.1% digestive problems, 30.2% cardiac pathology, 28.8% respiratory diseases, 28.4% neoplasia and 19.7% diabetes). About 80% of the patients reported mobility limitations.

'Neurological and oncological diseases, which are the most common indicators for HAN, accounted for 50% of indications in the registry. The remaining cases were malnourished patients who received limited periods of HAN after hospitalization or a hip fracture. So, 53% of the enrolled patients had a short duration of HAN, less than 2 months.'

At baseline, 78% of patients had malnutrition, mainly protein or mixed malnutrition.

HAN characteristics

Oral supplements were the most frequent type of HAN (60% of patients). Among patients with HAN by enteral access, nasogastric tubes and bolus administration by gravity systems were predominant. The percentage of gastrostomy was low (5%). No home parenteral nutrition was started in the study period. Standard and high-calorie formulas were the most reported in the present study, with the median energy intake provided by the HAN being 800 (IQR 2 437) kcal/day.

Caregiver profile

In our study population, 60.3% of patients had a home caregiver, but in the end, only 103 of them were included (Figure 2).

Regarding the most common caregiver profile, we found a mean age of 53.1 (s.d. 13.4) years and a clear predominance of females. Thus, the proportion of female caregivers was four times higher than that of male caregivers (*P* < 0.001). No differences in age were found between male and female caregivers.

The majority (78.8%) of patients had one primary caregiver, daughters/sons being the most common (50% of cases). Professional caregivers as the primary ones were very infrequent. The degree of kinship between caregivers and patients is summarized in Figure 3.

By contrast, in 21.1% of cases the role of primary caregiver was shared among several caregivers. In this group the daughters/sons were again the most frequent caregivers (46.6%), but 53.3% of patients had a professional caregiver as well.

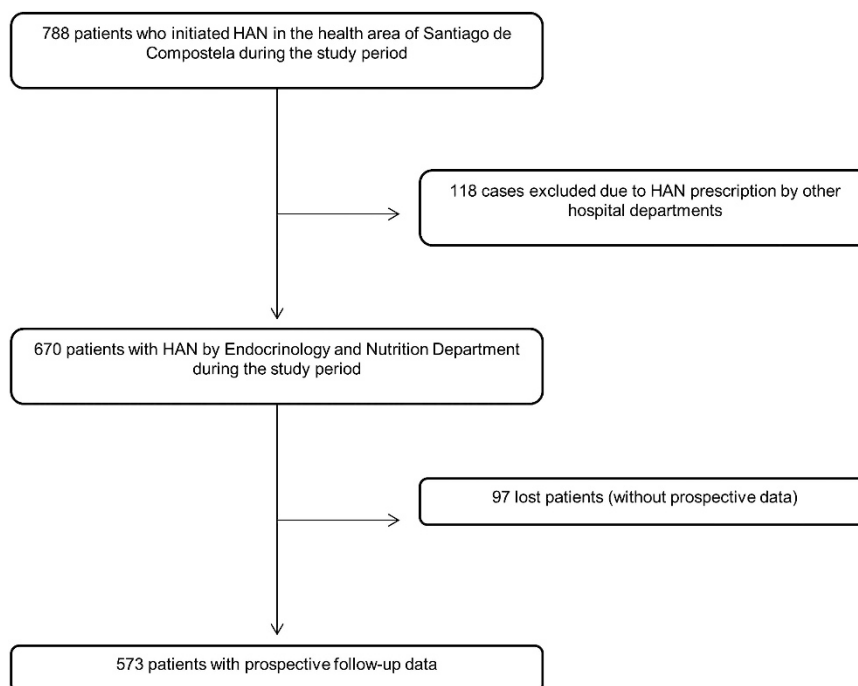


Figure 1. Flowchart of study patients.

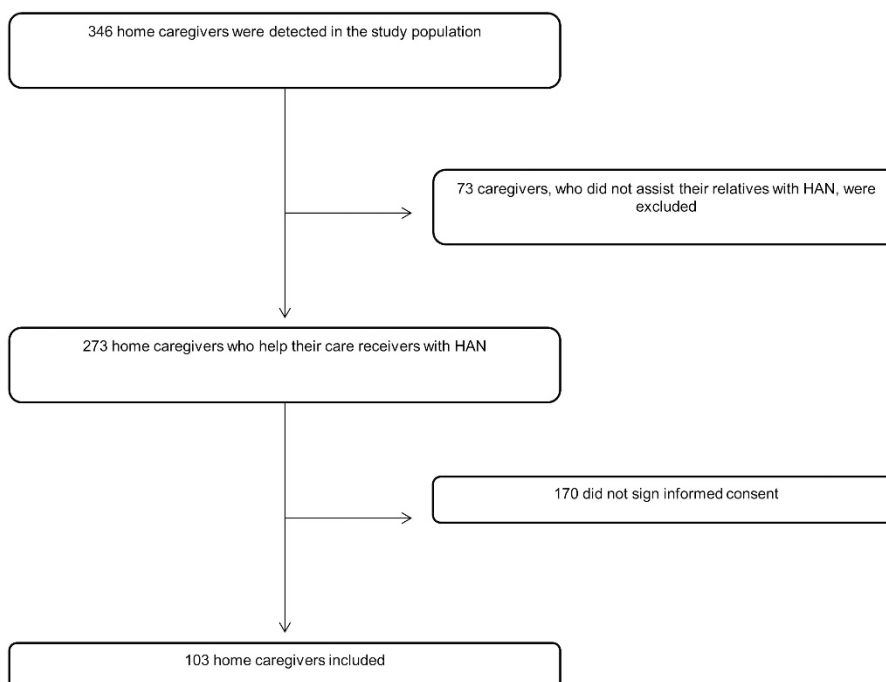


Figure 2. Flowchart of study caregivers.

Caregiver burden

The average burden score obtained from all the interviewed caregivers was 26.3 (s.d. 14.6) points out of 88 possible, using the original system, and 48.3 (s.d. 14.7) points out of 110 possible with the Spanish system. In the interviews conducted, the degree of burden was classified as follows: 49.5% as absence of burden, 18.4% as light burden and 32% as intense burden.

We found no differences in the degree of burden depending on the caregiver profile (gender, age, degree of kinship or presence of other caregivers). However, the type of nutritional support did affect the results. Thus, the percentage of caregivers with an intense burden was higher in oral over enteral HAN (42% versus 22.6%; $P=0.036$). In caregivers of patients with supplementary nutrition, we also found a higher Zarit score compared with complete diets (Table 1). No differences in burden were detected

according to the type of enteral access (nasogastric tube versus gastrostomy).

Regarding the relationship between caregiver burden and patient characteristics, only a trend toward higher scores in caregivers of patients with functional limitations compared with those with preserved mobility was evident, although it was not statistically significant (Table 2).

No differences between caregiver burden and other patient variables, such as the presence of obesity or severe malnutrition, were found.

Caregiver security in HAN management

One of the Zarit Interview items specifically asked about the existence of doubts or uncertainty in the management of HAN. In 83.3% of cases, the caregivers reported that they did not feel doubts or rarely, if ever, whereas only 16.6% showed occasional or very infrequent concerns. The difference between both groups was considered significant ($P < 0.001$).

In a univariate analysis, we could not identify any characteristics of the caregiver, of the nutritional support, or of the patient that affected the degree of confidence of the caregiver in the management of HAN.

DISCUSSION

Our evaluation of caregiver burden in the field of HAN showed that burden was present in the half of caregivers interviewed, and it was intense in a third of them. Moreover, the type of nutritional support was a determining factor, being oral supplementary nutrition associated with higher burden scores and higher

percentages of intense burden in comparison with complete nutrition by tube/ostomy. These results would support the inclusion of caregiver burden assessment in HAN programs and prompt the development of strategies to prevent it and improve it.

HAN has experienced great development in recent years as a way to prevent or treat malnutrition when nutritional requirements are not fulfilled with natural food. A large proportion of patients with HAN therapy tend to be older and dependent. Consequently, many patients will require a caregiver to help them with HAN. The Spanish registry published by the SENPE reported on its last records that 40–56% of patients require total aid for basic daily activities,^{18–20} and according to a European survey, only 17% of patients with home enteral nutrition can manage their nutrition therapy autonomously.²¹ In line with other published records, our study population showed high rates of aging, comorbidity and functional limitation (about 80%). This explains why the figure of the informal caregiver is essential for patient care at home to manage therapies like HAN. Nonetheless, very few studies in the literature have studied the role of the caregiver in this scenario and the burden they may suffer when in charge of a patient with HAN. The present study aimed to provide new data on the subject.

In the United States, according to the National Alliance for Caregiving and the American Association for Retired Persons, the typical caregiver is a 49-year-old female who is usually married and employed on a full-time basis. Caregivers provide care for 4 years on average, spending 24.4 h a week.²² In Spain, the Institute for the Elderly and Social Services (IMSERSO) describes the most common profile of caregivers of dependent patients as a patient's relative, especially middle-aged women (around 50 years), married, with no gainful occupation, who live with the patient and act as primary or sole caregiver in many cases. Sometimes they have to combine this task with the care of their children and grandchildren.⁷ This prototype of caregivers completely corresponds with the findings in our area. However, the low frequency of professional caregivers observed ($< 10\%$) contrasts with data in other European countries, where around 35% of caregivers are professionals, mainly nurses.²¹ Perhaps the peculiarities of the economic, social and familial structures existing in our country may explain these observed differences. The changes taking place in family patterns in recent decades could possibly affect the provision of care to dependent relatives (that is, the reduction in the number of children per family, the higher rate of dissolution of marriage, the increase in life expectancy and chronic diseases and women entering the working market). Despite these changes, in a predominantly rural area like ours, a sense of responsibility still persists in families about caring for older or dependent relatives. Moreover, the current economic crisis, the lack of public support and the high unemployment rate could also explain our high

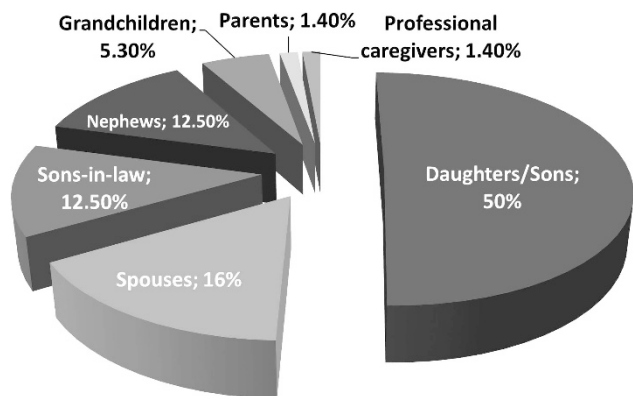


Figure 3. Relationship between patients and single primary caregivers.

Table 1. Caregiver burden scores according to HAN type

Zarit score	Caregivers of patients with supplementary nutrition	Caregivers of patients with complete diets	P-value
Original system mean (s.d.)	30.3 (16.1)	23.6 (13)	0.028
Spanish system mean (s.d.)	52 (16.1)	45.7 (13)	0.04

Table 2. Caregiver burden scores according to patient's mobility

Zarit score	Caregivers of patients with functional limitations	Caregivers of patients with preserved mobility	P-value
Original system mean (s.d.)	27.4 (14.7)	19.5 (12.4)	$P = 0.151$
Spanish system mean (s.d.)	49.3 (14.7)	41.5 (12.4)	$P = 0.147$

percentage of related caregivers and the rarity of professional ones.

The chronic stress experienced by caregivers may cause them serious physical, psychological or socioeconomic consequences and should be routinely evaluated. Caregiver burden has been studied mainly in caregivers of elderly patients with chronic diseases, neurological disorders (dementia and stroke) and cancer.²³ However, few data exist on the burden associated with caring for patients with HAN.

In the present study, the average score obtained in the Zarit Interview from the caregivers was similar to that reported in other groups, such as caregivers of patients with dementia,²⁴ although lower scores were found in caregivers of immobilized patients in a study of an area next to ours (Oroso, Spain).²⁵ It is noteworthy that nearly half of caregivers felt no burden. Furthermore, most caregivers stated that the task of caring for a dependent relative, especially a parent, was satisfactory and dignified them. Only 32% experienced severe burden, which is the most relevant for its association with major medical, psychiatric and social morbidity of the caregiver. Although less meaningful, 18.4% of caregivers reported light burden, which must also be considered because it is a risk factor for severe burden.^{8,14,26}

Regarding factors that may influence burden, no differences in burden grade or Zarit score according to caregiver characteristics (gender, age, kinship or being single or multiple caregivers) were found. Nevertheless, according to other studies, caregiver burden can be determined by factors such as the genre and the workload of the caregiver, the quality of the relationship between the caregiver and the patient, the experience of adverse life events, and the confidence level of the caregiver.²⁷ Older caregivers and those with a lesser degree of kinship, with occupations outside the home, with higher levels of education or living in urban areas have been shown to exhibit worse outcomes.²⁵

Other investigations have related patient characteristics to the degree of caregiver burden. The neuropsychiatric and functional impairment of the patient, the presence of behavioral disorders and the fact that caregiver and patient do not live in the same home are most commonly associated with burden and collapse.²⁸ In our work, we also found higher scores in caregivers of patients with greater functional limitations, although these differences were not statistically significant. By contrast, patient's nutritional status did not affect Zarit results.

Few studies have been conducted on caregivers of patients with HAN, and thus, available data are scarce. Caring for a patient with HAN may require an average of 61.87 h per week of dedication and is a task that requires prior training to really work well.²⁹ Caregivers of patients with HAN by tube previously reported that this treatment created a heavy responsibility, for which they often could not find enough support, and had dramatically changed their lifestyle.³⁰

However, to our knowledge, this is the first publication that assesses the burden on caregivers of patients with HAN. In our health area, we found a lower burden on caregivers of patients with complete nutrition and a lower percentage of intense burden associated with tube feeding compared with oral supplements. We can assume some of the reasons that could account for these results. After proper training of the caregiver, tube feeding is perhaps easiest to handle, thanks to the security and efficiency it provides. The use of commercial formulas guarantees the required nutritional intake, avoiding the problems or deficiencies in textures of a traditional oral diet. Instead, the caregivers of patients with oral nutritional support may have more difficulties ensuring that their relatives consume both diet and supplements. On the one hand, combining foods properly to achieve balanced and adequate mixtures with safe swallowing texture can be a complicated task. On the other hand, oral supplements are sometimes rejected by malnourished patients due to anorexia or digestive symptoms like nausea or satiety, and also, several

patients refuse to eat nothing but natural food. These situations can be challenging, meaning a constant struggle between the caregivers and their relatives, generating doubts, insecurity and ultimately, greater caregiver burden.

Finally, as a limitation of this study, we have to point out that a control group of caregivers of similar patients without HAN would be necessary to determine the real influence of this therapy in the burden degree.

CONCLUSIONS

Caregiver burden constitutes an enormous challenge, due to its serious effects on the caregiver's health, well-being and the quality of care offered to their relative. HAN type appears to be a factor influencing caregiver burden. Therefore, evaluation of caregiver burden should be part of HAN programs, to design strategies to prevent and reduce its severe repercussions.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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