

## Informal caregivers on home enteral nutrition need knowledge, skills and professional support

Cuidadores informais em nutrição enteral domiciliar necessitam de conhecimentos, habilidades e apoio profissional

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### Abstract

**Objective:** To assess effectiveness of informal caregivers in administering home enteral nutrition (HEN). **Casuistic and Method:** Patients scheduled for hospital discharge with the use of HEN were selected during hospitalization. Twenty-two patients and their caregivers were visited at home 4 days after discharge from the hospital. During the visit, the preparation and administration of 1 enteral feeding bottle by the caregiver were observed and possible mistakes made during the process were recorded. The quality of life of the caregivers was determined by applying the World Health Organization Quality of Life – Bref (WHOQOL Bref.) questionnaire and the nutritional status of the patients was analyzed by calculating the body mass index. **Results:** Most of the informal caregivers were unable to offer appropriate HEN. Ninety percent of them did not follow recommendations about hygiene such as hand asepsis or disinfection of the utensils and 70% did not prepare the enteral diet in an appropriate manner according to prescription and guidelines, using a smaller amount of the powdered diet and offering fewer calories to the patients (approximately 500 kcal/day). The caregivers themselves (73%) reported difficulties in understanding the instructions provided at discharge from the hospital and their quality of life was classified as medium-high. Most patients (59%) were found to be malnourished and had a calf circumference of less than 31 cm (73%). **Conclusion:** The caregivers were not efficient or effective in offering HEN and made mistakes during the process. Informal caregivers need homecare service for training and monitoring by a professional multidisciplinary team since they do not have the necessary competence and knowledge for appropriate HEN administration.

**Key words:** enteral nutrition, caregivers, quality of life.

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## Resumo

**Objetivo:** Avaliar a eficiência de cuidadores informais em fornecer dieta enteral domiciliar.

**Casuística e Método:** Foram selecionados, durante internação hospitalar, pacientes com previsão de alta em uso de dieta enteral domiciliar. Vinte e dois pacientes e cuidadores foram visitados em suas casas após 4 dias da alta hospitalar. Em visita domiciliar, foi observado o preparo e administração de 1 frasco de dieta enteral pelo cuidador, anotando possíveis erros durante o processo. A qualidade de vida dos cuidadores foi obtida pela aplicação do questionário World Health Organization Quality of Life – Bref (WHOQOL Bref.) e o estado nutricional dos pacientes foi analisado pelo cálculo do índice de massa corporal. **Resultados:** A maior parte dos cuidadores informais foram incapazes de oferecer dieta enteral domiciliar apropriada. Observou-se que 90% dos cuidadores não seguiram recomendações sobre higiene, como assepsia das mãos ou desinfecção de utensílios. A maior parte dos cuidadores (70%) não preparou adequadamente a dieta enteral conforme prescrição e orientação, utilizando quantidade menor da dieta em pó e oferecendo menos calorias aos pacientes (aproximadamente 500 kcal/dia). Os próprios cuidadores (73%) relataram dificuldades para compreender orientações da alta hospitalar e apresentaram qualidade de vida classificada de média-alta. A maior parte dos pacientes apresentaram desnutrição (59%) e circunferência da panturrilha menor que 31cm (73%). **Conclusão:** Cuidadores não foram eficientes e eficazes em oferecer HEN e apresentaram erros durante o processo. Cuidadores informais precisam de serviço de homecare para treinamento e acompanhamento por equipe profissional multidisciplinar. Falta competências necessárias e conhecimento para os cuidadores informais oferecerem HEN adequadamente.

**Palavras chaves:** nutrição enteral, cuidadores, qualidade de vida.

## Introduction

Enteral Nutrition is administered through a tube into the stomach or into the small bowel. Home Enteral Nutrition (HEN) is indicated for patients who cannot meet their nutritional requirements by oral intake, who have a functioning gastrointestinal tract and who are able to receive therapy outside an acute care setting.<sup>1</sup>

For appropriate HEN administration, patients and their relatives must be trained

and advised by a qualified multiprofessional team.<sup>2</sup> This type of care is complex and requires special attention to the training of informal caregivers.<sup>3</sup> In addition to the difficulty in offering HEN, a task assigned to the caregiver often without the support of health institutions, the changes in routine and the time spent in providing care may have an impact on the quality of life of these persons.<sup>4</sup> Andrade et al.<sup>5</sup> observed that caregivers are deprived of their leisure activities, with

consequent social interaction deficits in addition to a reduced family income. Caregivers experience feelings of loneliness possibly due to the fact that they feel that they should not ask for help even when they are overworked. Bento et al.<sup>2</sup> observed that the impaired quality of life of caregivers in charge of elderly patients or patients with cancer is mainly due to the demands of the care they provide and to the overwork and stress they experience. By analogy, we may suggest that caregivers of patients on HEN are submitted to the same levels of physical, social, family and psychological stress.

Smith<sup>6</sup> described the term "caregiving effectiveness" as "provision of technical, physical and emotional care that results in outcomes of optimal patient quality of life and physical condition, minimal technological side effects for the patient, and the maintenance of caregivers' health and quality of life."

The health care systems of various countries are based on private home care companies who can teach and provide caregivers and supervise patients and caregivers in the home environment, offering a better quality of life to both patients and informal caregivers. In these cases, individuals must pay for this type of care. Brazil has private home care companies and a Public Health System (SUS) that ensures health care to the entire population. In 2011 the government implemented home care

services through SUS.<sup>7</sup> The SUS cannot cover 100% of the HEN demand in Brazil. In regions without follow-up home care services, informal caregivers receive instructions at the public hospital at the time of patient discharge and need to manage all home care technologies by themselves. Considering the increase of HEN in Brazil, the objective of the present study was to assess "caregiving effectiveness" in managing HEN without follow-up home care service.

## **Casuistic and Method**

### **Subjects and procedures**

Forty-one patients of both genders receiving an enteral diet during hospitalization and with a discharge plan for HEN were recruited from the hospital Santa Casa de Misericórdia de Franca, Franca (SP, Brazil) from April to July, 2012. At discharge, the study was described to both patients and caregivers, home contact information was obtained and a day for a home visit after discharge from the hospital was scheduled. Written informed consent was obtained from all subjects. The study was approved by the Medical Ethics Committee of the Hospital Fundação Santa Casa de Misericórdia de Franca (Process 113/2011). Inclusion criteria were: patients discharged from the hospital while receiving enteral nutrition, and patients and caregivers of both sexes residing in the city of Franca. Patients and caregivers who for any reason were

unable to receive the scheduled home visit for data collection were excluded.

Four days after discharge, a one-day home visit was conducted. The number of patients was reduced from 41 to 22 because of subsequent mortality. During the home visit (about 70 minutes) the caregiver was observed while providing HEN to the patients and all mistakes were recorded, as shown in **Figure 1**. Information about difficulties during HEN and quality of life was obtained from the caregiver and the nutritional status of patients was evaluated.

It is important to emphasize that informal caregivers or family caregivers received instructions about the proper offer of HEN from a dietician over a period of approximately 30 minutes. They were advised about personal hygiene, tool cleaning, how to keep the patient in a 45° position during feeding and how to prepare both industrialized and home-made formulas. The

caloric content of the formulas prescribed by dietitians usually ranges from 900 to 1500 kcal, according to the patient's nutritional needs. The formulas are provided by SUS and, before they are delivered, the caregivers are advised to use enteral diet recipes. The enteral diet is usually administered six times a day during 1 to 2 hours of infusion, and all equipment is provided by the hospital.

### **Caregiver's characteristics and reported difficulties in managing HEN**

The variables studied were caregivers' profile, challenges about the job, the relationship with the patient, payment of home care service, and number of caring hours.

To measure caregiving effectiveness, the caregiver was observed while preparing and offering the enteral diet to the patient from the beginning to the end of the process. The variables observed (yes or no) are illustrated in **Figure 1**.

<p><b>Hygienic Aspects</b></p> <p>Washing hands using aseptic/sterile technique</p> <p>Clean and short nails</p> <p>Caregiver wear a medical cap or holding hair</p> <p>No loud, earrings, necklaces, rings</p> <p>Disinfecting tools with alcohol or sodium hypochlorite</p> <p>Cross contamination (avoid contact with other diet not sanitized places)</p>
<p><b>Diet manipulation and feeding process</b></p> <p>Measuring the amount of properly powder diet quantity of water</p> <p>Potable water or boiled water</p> <p>Offering enteral diet with 45° position of patient</p>

Figure 1 – Components observed during the enteral diet administration

The quality of life of the caregivers was determined by applying the WHOQOL Bref questionnaire, validated by Fleck et al.<sup>8</sup> for use in the Brazilian context. The Portuguese version of the WHOQOL-BREF consists of four domains: Physical Capacity (7 items: pain and discomfort; energy and fatigue; sleep and rest, daily life activities, dependence on medication or treatment, ability to work), Psychological Well-being (6 items – positive feelings; thinking, learning, memory and concentration; self-esteem; body image and appearance; negative feelings; spirituality/religion/personal beliefs), Social Relationship (3 items – personal relations; social support; sexual activity), and Environment (9 items – physical safety and protection; home environment; financial resources; health and social care; availability and quality; opportunity to acquire new information and skills; participation in, and opportunity for recreation/leisure; physical environment: (pollution/noise/traffic/climate); transportation). The results were obtained by scoring the responses from 0 (worst) to 100 (best), with no single value summarizing the entire assessment, resulting in a better or worse general state of quality of life.<sup>8</sup>

#### **Evaluation of Patient's Nutritional Status**

Data regarding height, mid-arm circumference, calf circumference, and knee height were collected. Weight and height

were estimated according to hospital estimative equations because the sample consisted of bedridden patients.<sup>9</sup> The Body Mass Index (BMI) was used to classify the patients' nutritional status and was calculated and analyzed according to the classification of WHO (adults) and Lipschitz (elderly).

#### **Statistical Analysis**

Descriptive statistics were used to summarize the data for all variables. The continuous variables are reported as mean and standard deviation and the categorical variables as frequency and percentage.

### **Results**

#### **Nutritional status of HEN patients**

The mean of age of the patients was  $76 \pm 6$  years (19 patients were older than 60 years). Almost 50% of the patients had motor skill problems. The main factors that had led to the prescription of HEN for the patients were: dysphagia (68%, 15/22) and anorexia (22%, 5/22). Almost 100% of the patients (21/22) received HEN by a nasogastric tube. All patients received a high-calorie and high-protein diet with a polymeric formula (1.5 kcal/ml) during hospitalization, and the same diet was prescribed for HEN. Even within a short time after discharge (4 days), the caregivers mentioned HEN complications such as accidental tube misplacement (**Table 1**).

**Table 1 - Clinical complications after 4 days from discharge in relation to home enteral nutrition.**

Complications in HEN	%	N
Accidental tube misplacement	36%	8
Intestinal Constipation	18%	4
Tube clogging	17%	3
Sickness and vomit	17%	3
Other complications*	9%	2

\*Swollen/distended stomach, skin redness in the area of the tube and cramps.

It is important to note that, during the study period (April to July, 2012), hospital dietitians and nurses reported to the investigator 13 (59%) readmissions of HEN patients, ten due to aspiration pneumonia, two as a result of pressure ulcer and one because of secretion in the tube area.

Regarding nutritional status, 59% (13/22) were underweight and 73% (16/22) had a calf circumference of less than 31 cm.

#### **Caregivers' effectiveness and difficulties in managing HEN**

All informal caregivers were females and were relatives of the patients. Fifty-four percent (12/22) had completed only primary school, 36% (8/22) had attended secondary

school and 23% of the latter (5/12) had not completed it. Only 9% (2/22) had a college degree. Their median age was  $54 \pm 16$  years, they were unpaid and lived with the patients. The caregiving (100%) lasted 24 hours a day, and five of them had to abandon their jobs.

Most caregivers reported technical difficulties during the feeding procedure (**Table 2**). Seventy percent reported that they could not properly understand the instructions received at hospital discharge. In their own words, "it's very difficult to get the whole information at once and I forgot what I should do" and "it's so much information to understand at once, I feel afraid to make a mistake".

**Table 2 – Difficulties according to the caregivers (n=22) on offering home enteral nutrition.**

Difficulties on offering HEN	%	N
Difficulties to understand the instructions	69	15
Maintaining the patient in a 45° position	38	8
Preparing and diluting the enteral formula	23	5
Giving the enteral diet in correct time	17	3

Table 3 lists the tasks of the HEN caregivers observed during the home visit. Most caregivers were unable to perform HEN correctly, 90% of them having problems with at least one hygiene aspect. Considering the task "washing hands using an aseptic/sterile technique", 27% (6/22) did not even perform the procedure and 23% (5/22) performed it in

the wrong way. During diet preparation, 72% (n=16) did not disinfect any tool with 70% alcohol or sodium hypochlorite. Furthermore, when preparing the diet, 70% (n=15) of the caregivers did not prevent contact between the enteral formula and the environment, for example the sink, the table and food waste.

**Table 3 - Home Enteral Nutrition caregiver tasks observed during home visit.**

<b>Hygienic Aspects</b>	<b>% (n)</b>
Washing hands using aseptic/sterile technique	36% (8/22)
Clean and short nails	45% (8/22)
Caregiver wear a medical cap or holding hair	23% (5/22)
No loud, earrings, necklaces, rings	45% (8/22)
Disinfecting tools with alcohol or sodium hypochlorite	28% (6/22)
Cross contamination (avoid contact with other diet not sanitized places)	30% (7/22)
<b>Diet manipulation and feeding process</b>	
Measuring the amount of properly powder diet quantity of water	30% (7/22)
Potable water or boiled water	100% (22/22)
45° position of patient	81% 20/22

The diet was incorrectly prepared by 70% (n=15) of the caregivers. The amount of powder prescribed by the nutritionist was used in the preparation, but the caregivers used another commercialized enteral formula with different caloric density. As a consequence, the patients did not achieve their recommended daily calorie intake, receiving an average of 500 calories less than prescribed. Also 60% (n=13) of the caregivers did not dilute the formula as recommended.

### **Caregivers' quality of life**

When answering the question "How would

you rate your quality of life?", most caregivers rated it as good (77.2%). **Table 4** presents the score distributions of each domain. The mean overall quality of life score was 59%, indicating that the participants' quality of life was of medium-high level. The domain receiving the best score was social relationships (67%) and the domain receiving the worst score was the environment (53%), where no single value summarized the entire assessment, resulting in only a definition of a general state of better or worse quality of life.

**Table 4: Score distributions of four domains and the Overall Quality of Life and General Health facet of the WHOQOL-BREF among 22 informal caregivers.**

Domain or facet	Frequency (%)	Mean $\pm$ SD	Variation coefficient	Minimum	Maximum
Physical Capacity	59%	13,40 $\pm$ 2,11	15,72	8,00	16,00
Psychological Well-being	61%	13,73 $\pm$ 1,93	14,03	9,33	17,33
Social Relationships	67%	14,79 $\pm$ 1,42	9,60	12,00	17,33
Environment	53%	12,50 $\pm$ 1,10	8,82	10,50	14,50
Overall Quality of Life	59%	13,43 $\pm$ 1,26	9,41	9,85	15,08

## Discussion

Longer life spans and the use of healthcare technology have contributed to a large number of informal caregivers, who experience benefits and challenges in their role. The challenges may lead to numerous economic, physical, or psychosocial stressors. It was observed in this study that caregivers need training for multiple nutrition-related functions and caregiving tasks.

Almost no caregivers followed instructions about hygiene, exposing the enteral diet to contamination, a fact that could lead not only to diarrhea, but also to sepsis, pneumonia, and urinary tract infections. Borges et al.<sup>10</sup> reported unsatisfactory sanitary-hygienic conditions in two Brazilian hospitals, where hand contact was probably one of the sources of greatest significance for enteral diets contamination. Infections during enteral feeding are usually due to lack of proper hygiene while manipulating the formula, or to the inability to disinfect the equipment during preparation.

One of the most important results of the present study was that caregivers (70%) measured a smaller amount of powder diet for the same quantity of water. This resulted in lower caloric density of the enteral diet and consumption of fewer calories than recommended, with consequent possible changes in patients' nutrition status. The caregivers only memorize the amount to be used in the preparation without taking into account the fact that each kind of enteral diet has different calories per gram. In practice, they obtained other commercialized enteral diets from relatives or friends but used the same amount of powder recommended independently of caloric density. According to Vasconcelos and Tirapegui<sup>11</sup>, changes in nutritional status could be the consequence of an inadequate amount of nutrients or metabolic changes. Either way, the result is the same, i.e., malnutrition, with aggravation of the patient's pathology. Also, tube clogging could be caused by improper dilution of the enteral diet by the caregiver, because 60% of

caregivers did not first dilute the formula in a small amount of water but immediately added the entire amount of water. The mistakes made by the caregivers when offering HEN may be due to lack of formal training, with consequent learning from experience and on the basis of information obtained from other persons or from the internet. Mistakes could be due to inadequate training and could predict the development of caregiver burden.<sup>12</sup>

None of the caregivers had excellent education, and many of them did not even complete secondary school. Most caregivers had difficulties in properly understanding the enteral nutrition instructions, a fact that may expose the patients to aggravation of their condition and nutritional status. The educational level of the caregivers could explain, at least in part, the results, emphasizing the need for training and the importance of multiprofessional follow-up home care services. Fonseca et al.<sup>13</sup> emphasized that an appropriate educational level is mandatory to guarantee that the caregivers are fairly prepared to do the home care service alone. The health system currently favors dehospitalization, but to achieve this goal it is necessary to create appropriate strategies to satisfy the needs of both patients and caregivers.<sup>3</sup> Waitzberg et al.<sup>14</sup> have proposed the elaboration of a manual in order to help and monitor the family and to prevent possible complications

of the method. Silver et al.<sup>4</sup> pointed out that the efficacy of nutritional therapy requires more frequent monitoring as well as reassessment and intervention by a highly qualified multidisciplinary team that includes dietitians. Silver et al.<sup>4</sup> studied 30 older adults and their informal caregivers with the objective of applying care process theory to identify and investigate variables related to health care outcomes. The home visit was held 4 to 12 weeks after discharge, investigating patient's characteristics, HEN regime prescription and adherence, formal provider involvement, and health care outcomes. The study concluded that it is essential to have a frequent monitoring of these patients, including a multidisciplinary team with a dietitian. The study also cited that it is a challenge to meet the aim of HEN in today's situation of healthcare, with difficulties combined with early discharge, too short a time of caregiver training, and limited availability of multidisciplinary home care services.<sup>4</sup> The public health system must create strategies that would successfully meet all the patient's and caregiver's needs.

## **Conclusion**

Although the present study had a small sample size and a short time of observation, it was concluded that caregivers were not prepared to manage HEN without a follow-up home care service. Caregivers were not effective in managing HEN and committed

mistakes during the process due to insufficient skill and knowledge. In order to achieve successful HEN, the caregivers should be adequately instructed and monitored by a multidisciplinary healthcare team according to their educational level. Reaching the goal required by HEN is a challenge in the current health care environment in which several shortcomings contribute to this inadequate scenario involving an early discharge, a short time of educational counseling for the family and the caregivers, reduced availability of community support, the absence of multidisciplinary monitoring of patients on HEN, and the reliance on informal caregivers for this practice, compounded by the lack of the minimum necessary education.

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