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## **Possibilities and limitations of enteral nutritional therapy based on the perspective of caregivers and professionals from a public health network in a border region**

*Possibilidades e limitações da terapia nutricional enteral na compreensão de cuidadores e profissionais de uma rede pública de saúde em região de fronteira*

### **Abstract**

*Objective:* Analyzing the possibilities, limitations and challenges of home enteral nutrition therapy in the public health network and the nutritional profile of post-hospital patients living in Foz do Iguaçu County, Paraná State, Brazil. *Methodology:* Cross-sectional and qualitative-quantitative study. Sample: 12 individuals subjected to home enteral nutrition (with, and without, nutritional monitoring); 12 caregivers and 8 health professionals. Data collection was based on nutritional anamnesis (users) and on interviews with health professionals and caregivers. Interviews were recorded, transcribed and analyzed based on the theoretical perspective by Bardin. Inelastic tape and body fat caliper were used to generate patients' nutritional profile; results were compared to recommendations. *Results and discussion:* There was prevalence of female and adult individuals

among caregivers and health professionals, whereas elderly and female individuals prevailed among enteral nutrition patients. Seven patients fed on manipulated diet; the group without nutritional follow-up presented higher frequency of complications and deaths, as well as less satisfactory anthropometric profile. Caregivers were disoriented and insecure about how to apply enteral nutrition at home, mainly to patients who did not have nutritional follow-up. Health professionals and caregivers pointed out the importance of performing professional follow-up and of providing diets to patients after hospital discharge; weaknesses in the network due to lack of flow, standardized guidelines and referrals with network protocols about the application of home enteral nutrition therapy. *Conclusions:* Results showed the significant need of training caregivers, multi-professional and intervention teams in home care.

**Keywords:** Enteral nutrition. Home care. Network of continued health care.

#### Resumo

*Objetivo:* Analisar possibilidades, limites e desafios da terapia de nutrição enteral domiciliar na rede pública de saúde e o perfil nutricional de pacientes pós-alta hospitalar de Foz do Iguaçu, PR. *Métodos:* Estudo de delineamento transversal e quanti-qualitativo. Participaram do estudo 12 indivíduos usuários de nutrição enteral domiciliar (com e sem acompanhamento nutricional); 12 cuidadores e oito profissionais de saúde. Na coleta de dados, utilizaram-se anamnese nutricional (usuários) e entrevistas (profissionais e cuidadores). As entrevistas foram gravadas, transcritas e analisadas na perspectiva teórica de Bardin; para o perfil nutricional, utilizaram-se fita inelástica e adipômetro, comparando-se os resultados às recomendações. *Resultados e discussão:* Houve predomínio do gênero feminino e de adultos para cuidadores e profissionais, enquanto entre os indivíduos em nutrição enteral, de idosos e mulheres. Sete destes estavam sob dieta manipulada; a frequência de complicações foi maior no grupo sem acompanhamento nutricional, assim como de óbitos e perfil antropométrico menos satisfatório. Os cuidadores mostraram-se desorientados e inseguros em relação à condução da nutrição enteral no domicílio, sobretudo no grupo desassistido por nutricionista. Profissionais e cuidadores apontaram a importância de acompanhamento profissional após a alta hospitalar e de oferta de dietas; fragilidades na rede pela ausência de fluxo, orientações padronizadas e encaminhamentos; com



indicação de protocolo em rede para a condução da terapia de nutrição enteral domiciliar. *Conclusões:* Estes resultados mostram a notoriedade de formação dos cuidadores, equipe multiprofissional e intervenção gestora no cuidado domiciliar.

**Palavras-chave:** Nutrição Enteral. Atenção domiciliar. Rede de cuidados continuados de saúde.

## INTRODUCTION

As chronic disease, accident and elderly population rates increase in the country, the number of hospitalizations, deaths and discharges to home care also increases; therefore, many patients have their dietary needs met through enteral nutrition.<sup>1,2</sup>

Enteral nutrition is an ancient procedure performed to meet patients' nutritional and hydration needs in case of inefficient or impaired physiological pathways. It is characterized by the direct administration of liquid food and nutrients (nutritional solutions presenting chemically-defined formulas) through probes introduced in patients' small intestine or stomach.<sup>3,4</sup>

It is possible applying home enteral nutritional therapy (HENT) by providing nutritional and clinical assistance to post-hospital patients. HENT can be orally, enterally or parenterally applied to help recovering, or maintaining, patients' maximum health, functionality and comfort levels, as continuation of the care previously provided in hospital environment.<sup>4</sup>

Home care has important benefits; however, the administration of enteral nutritional therapy requires basic conditions such as hemodynamic and metabolic stability, tolerance to this dietary prescription type, qualified caregivers, suitable home environment and professional follow-up.<sup>4,5</sup> It is necessary making physiological, technical and psychosocial interventions to assure success in this therapy, given the importance of better understanding attitudes taken by patients and caregivers towards the need of using feeding probes.<sup>6</sup>

If one takes into consideration the variety of diets and formulas developed for enteral nutrition purposes, the administration of industrialized diets based on defined formulas presents benefits, since they do not require secondary handling. However, these diets represent high-costs for the public health network, since there is no specific funding for home enteral nutrition therapies, which are often expensive, fact that hinders patient adherence to treatment. Most counties are responsible for carrying out their own planning, although

food is a constitutional right.<sup>1,3</sup> In addition, universally accepted and standardized home enteral nutrition protocols remain scarce,<sup>7</sup> as well as studies about HENT, which are often restricted to certain regions.<sup>7-9</sup>

Thus, the aim of the current study was to analyze the possibilities, limitations and challenges of home enteral nutritional therapy in the Public Health Care Network (HCN) of Foz do Iguaçu County (PR) - a county located on the border line with Ciudad del Este (Paraguay) and Puerto Iguazu (Argentina) -, as well as the nutritional profile of patients subjected to this post-hospital discharge therapy. The perception of caregivers and health professionals about the herein addressed process was taken into consideration in the current study due to the observed fragilities in the essential interdependence between complexity levels in this health care network, and given the importance of this therapeutic support to enable patients' adequate nutritional status.

## METHODS

The current study was conducted from March to December 2017, based on a cross-sectional design. It predominantly adopted a qualitative approach, although it analyzed facts and events in the life context of patients subjected to clinical-nutritional intervention based on home enteral therapy, besides evaluating quantitative aspects such as anthropometric and nutritional data through comparative analysis. Some quantitative variables enabled the broad analysis of the nutritional care process associated with factors linked to the historicity of relationships among professionals, caregivers and patients subjected to enteral nutrition, by taking into consideration a complex and deeply-dynamic context that even establishes possible contradictions.

Therefore, the current study analyzed the subject based on the dialectical method by Triviños,<sup>10</sup> according to whom patients' participation in the pursuit of results is one of the principles of scientific doing. This method is based on social practices adopted to find explanations for society's phenomena.

Foz do Iguaçu is the largest Brazilian border county in the far West of Paraná State, in a tourist region of triple frontier - Foz do Iguaçu (Brazil), Ciudad del Este (Paraguay) and Puerto Iguazu (Argentina), which faces visible social inequalities. Border residents have been moving between these cities since the 1970s, thus creating different forms of circulation and cross-border flows in the region. Therefore, this phenomenon also has consequences on the health system of Foz do Iguaçu, since migratory and tourist flows have significantly increased its "floating population" (national and international immigrants, tourists, students from other states and countries, the border population living in Paraguay and, to a lesser extent, in Argentina), who has been using the county's public health system.<sup>11,12</sup>



Nowadays, the county where the current study was carried out adopts the Full Management modality, which comprises 37 family health teams (FHT) accredited by the Ministry of Health to assist approximately 45.87% of the population. The county is divided into five health districts, where the Family Health Units (FHU) are distributed as follows: Northern (seven FHUs), Northeastern (five FHUs), Eastern (six FHUs), Central (six FHUs) and Western (five FHUs).

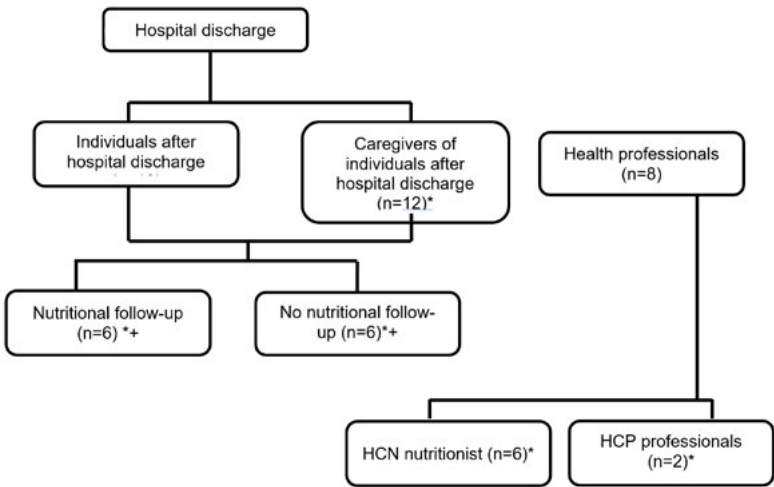
These districts count on Family Health Support Centers (FHSC), although only the Northern, Northeastern and Eastern ones have such structure, thus totaling three modality-1 nuclei in the county; however, none of them have a full multiprofessional team yet. The list of professional members comprises physical therapists, social workers, psychologists and nutritionists. These professionals compose the teams working in the three FHSCs and reported having a hard time covering the districts themselves due to lack of human resources and to the characteristic of the local work to be developed in these nuclei. It is worth emphasizing that the public service does not provide nutritional assistance to patients, except for the PHSC. In addition, the county also has an expanding Home Care Program (HCP) comprising a nurse and a nursing technician; the program is based on family health strategies focused on home care.

The municipal hospital has 210 beds divided into nursing wards, pediatrics, orthopedics, psychiatry, medical clinic, surgical clinic, emergency room and intensive care unit. Nowadays, it counts on three nutritionists, who provide clinical care to patients and divide their responsibilities among different sectors. Patients' diet during hospitalization is monitored by these nutritionists and prepared by an outsourced nutrition sector. Industrialized enteral diets are provided to patients and added with modules, whenever necessary. At the time patients are discharged from hospital, different health professionals working in the institution are instructed on how to provide home care, based on patients' needs and specificities. Patients' family must seek judicial assistance to receive industrialized enteral diets; however, it often takes a significant amount of time, besides requiring bureaucratic processes mostly unknown to both the population and health professionals.

Based on these aspects, individuals participating in the current study were divided into three groups: 12 users who were hospitalized at the municipal hospital and who were prescribed home enteral nutritional therapy at hospital discharge time; 12 caregivers of these users; and health professionals - three FHSC nutritionists, three from the municipal hospital and two professionals from the Home Care Program. The group of users was subdivided into two categories: one without nutritional follow-up after hospital discharge and the other one with nutritional follow-up by a FHSC nutritionist. Each group comprised six users.

Data collection was based on semi-structured interviews conducted with caregivers and health professionals, and on the home nutritional assessment of patients subjected to enteral therapy who were not interviewed because they were not able to orally communicate at research time (Figure 1). Nutritional anamnesis and different questionnaires were developed to be answered by health professionals and caregivers.

**Figure 1.** Flowchart of qualitative and quantitative data collection. Foz do Iguaçu County, Paraná State, 2018.



\* Interview and qualitative data collection; + Anamnesis and quantitative data collection.  
HCN (Health Care Network); HCP (Home Care Program).

Source: Prepared by the authors, 2018.

Health professionals were approached in the course of the research. Data about caregivers and enteral therapy patients were collected after hospital discharge. An anamnesis document prepared by the researcher was applied to the group without nutritional follow-up. This instrument was also used to collect information about the group with nutritional follow-up, besides the evaluations about the performance of health professionals.

The group without nutritional follow-up was visited by the researcher approximately three weeks after hospital discharge to investigate facts and events triggered by unassisted enteral therapy, to collect anthropometric and nutritional data, and to perform interviews. The group followed-up by the FHSC nutritionist was visited by the researcher, who observed the follow-up interventions right after hospital discharge for three weeks, thus resulting in two home visits; quantitative data cover 15 days after the hospital discharge of both groups.

The anthropometric evaluation was based on weight (kg); height (cm); mid-arm muscle (MAMC) and calf circumferences (CC); triceps (TSF), biceps (BSF), subscapular (SSSF) and suprailiac skinfolds (SISF); and knee height (KH). Circumferences were measured with an inelastic tape measure, whereas skinfolds were measured with a Cescorf scientific plicometer. All patients undergoing enteral therapy could not have their weight and/or height measured; thus, these parameters were estimated through equations based on patients' gender, race and age.<sup>13,14</sup> Patients' body mass index (BMI) was calculated and classified based on age-related recommendations.<sup>15,16</sup> Muscle mass was assessed through mid-arm muscle circumference (MAMC); its suitability was estimated based on sex and age,<sup>17</sup> and classified based on CC, according to Chumlea et al.<sup>18</sup> Body fat (BF) percentage was calculated based on the estimate suggested by Durnin & Womersley<sup>19</sup> and classified according to Lohman.<sup>20</sup>

With respect to enteral diet types, diets exclusively comprising food in natura were classified as homemade; the ones comprising nutrient modules were classified as modular; industrialized diets were classified as defined formula; and the association between homemade and modular categories was classified as mixed diet.<sup>3</sup> Information about complications associated with this therapy was also collected. In order to do so, these complications were divided into three categories (mechanical, metabolic and gastrointestinal) and the frequency of different complications was recorded for each group. Thus, each category comprised more than one type of complication experienced by the patients.

Interviews were recorded and immediately transcribed in order to be organized based on the data categorization system adopted in the content analysis by Bardin.<sup>21</sup> It was done to investigate the main, and most recurrent, ideas expressed in interviewees' responses in order to form cluster categories based on similar, or exhaustively mentioned, topics.

Data were organized in Microsoft Excel® spreadsheet. The software was also used to perform descriptive analyses based on means, percentages and standard deviation.

The project was approved by the Ethics Committee of Western Paraná State University - protocol N. 66931217.6.0000.0107 – and met the ethical criteria on human research set by CNS Resolution 466/2012. Caregivers and health professionals were interviewed after signing the Informed Consent Term and being assured about the anonymity of their information. The group of caregivers authorized the anthropometric evaluation of patients undergoing home enteral nutritional therapy.

RESULTS AND DISCUSSION

Two categories were structured based on the analysis applied to the current results: 1) *Hospital discharge and the management of home enteral nutrition*, which showed the complex operationalization of home nutritional care mostly provided by family caregivers; and 2) *"I'm lost!" - The mismanagement of information flows and referrals*, which pointed out the need of having effective communication through well-articulated dialogues in the primary care scenario, since it would enable the continuity of home enteral nutritional care services. These thematic categories were completed with quantitative data deriving from the evaluation of patients' nutritional profile and enteral therapy-related complications.

Ten (10) out of the 12 participants subjected to home enteral nutrition therapy were elderly women; adult women prevailed among caregivers (Table 1).

Table 1. Study participants' profile. Foz do Iguaçu County, Paraná State, 2018.

Group		Age group				Sex		
		Adult	Elderly	Mean Age	Age SD	Female	Male	
Individuals under HENT	With follow-up	n	1	5	73.50	9.38	3	3
		%	16.67	83.33			50.00	50.00
	Without follow-up	n	1	5	71.83	11.89	5	1
		%	16.67	83.33			83.33	16.67
Caregivers	With follow-up	n	6	0	39.67	11.10	5	1
		%	100.00	0.00			83.33	16.67
	Without follow-up	n	5	1	37.83	12.20	2	4
		%	83.33	16.67			33.33	66.67
Home Care Program (HCP)		n	1	1	58.50	3.50	2	0
		%	50.00	50.00			33.33	0.00
Nutrition Professionals		n	6	0	32.50	4.96	6	0
		%	100.00	0.00			100.00	0.00

Source: Prepared by the authors, 2018.

Most caregivers were relatives of patients in this group; they were instructed by the hospital nutritionist about the application of enteral nutrition therapy after hospital discharge. All health professionals participating in the current study were women and the health professional from the Home Care Program was elderly (Table 1).

Hospital discharge and the management of home enteral nutrition therapy: “we also need help at home”

The post-hospital discharge follow-up of users and caregivers, with and without nutritionist supervision, enabled perceiving significantly different realities concerning both the confidence of caregivers in performing enteral nutrition procedures in the daily routine of the household and the incidence of complications throughout the evolution of patients' health status. Seven patients in this group fed on manipulated diet, two fed on homemade diet, and five fed on homemade diet added with energy supplements. The other patients fed on industrialized diets purchased with their own financial resources.

Based on the number of patients fed on manipulated diets, it was possible seeing a worrying factor in the speech of a health professional who perceived lack of energy standard in it. The diets were often prepared at home, according to the caregivers' skills, fact that was also associated with the need of professional orientation:

[...] the industrialized diet already comes at the right point, with the right dose of all vitamins and nutrients the patient needs. The other diet does not; they do not put the same amount of protein and vitamin the patient needs on a daily basis ... It gets thick and they try to dissolve it by adding more water, more milk ... (Nursing Technician from the Home Care Program, 55a.).

[...] we are not instructed ... We are not ... If we cannot make it at home, the county should bear the cost of this food and give it to these bedridden patients. Authorities should pay more attention to bedridden patients discharged from hospitals [...] they also need help at home. They need it very much. (Caregiver 8, 34a., without follow-up).

Based on their experience, caregivers assisting patients without nutritional follow-up emphasized the need of being instructed by professional nutritionists, besides mentioning the importance of being assisted by multiprofessional teams. Enteral feeding was indicated as their main difficulty to adapt to the new routine, as observed in the speech of two caregivers:

Feeding her was the only difficulty I had. Just it. (Caregiver 4; 27a., without follow-up).

It was my concern. How am I going to treat my father through the probe? It would be very difficult for me [...]. Wow, I thought about it a lot, the probe was the thing that scared me the most (Caregiver 1, 41a., with follow-up).

The return of a family member to the household after hospital discharge can be a reason for joy, but also for anguish or stress,<sup>22</sup> as mentioned by some participants. According



to caregivers, not having access to the industrialized diet is a limitation in HENT, mainly due to the hard time preparing the diet and to lack of professional supervision, which makes caregivers insecure about the nutritional intake enabled by this dietary route.

[...] when we tried to sift it, it did not work, we did it on a piece of cloth and it did not work ... It kind of did not go down. [...] (Caregiver 4; 27a., without follow-up).

Non-standard cholesterol and salt doses ... Things like that can harm them. The industrialized diet already has the right nutritional doses [...] I think we will not be able to buy it. (Caregiver 11, 61a., without follow-up).

So, the difficulty lies on knowing we're doing the right thing. Knowing that it is ... that we're improving. If it is right ... So, I guess that's it, you know. Lack of confidence, you know. Lack of instructions provided by professionals. Being thoroughly instructed. I think it would be essential for the process to succeed, you know. And it is also our difficulty, right? (Caregiver 2, 35a., without follow-up).

It is not uncommon for caregivers working at home to have a hard time performing the necessary procedures to apply enteral feeding; such difficulty can be associated with both probe obstruction and food dripping. Dealing with enteral feeding can trigger feelings such as fear, anxiety, nervousness and restlessness, which expose caregivers to uncomfortable situations with strong emotional weight. However, this issue can be mitigated through instructions provided by health professionals.<sup>23,24</sup>

[...] I think it means everything, of course it means everything! It is the best thing, because we do not know some things very well, we have doubts, we want to know it right, then we think: can I do it, can I not do it, what am I going to do? You saw that I asked you a lot of questions, right? So, when I have doubts, I like to ask about them. So, I guess if we are going to do it, everything we do, we should ask questions to do it right [...] (Caregiver 10, 39a., with follow-up).

Oh, it is very important. It is very good. Because it clarifies my doubts. I was not giving enough water to her, now I can give her more water. And I know that if I have doubts you will clarify them for me. (Caregiver 9, 32a., with follow-up).

Other aspects of the same importance should be analyzed, besides the knowledge about the management of enteral therapies; among them one finds standard operating procedures and hygienic-sanitary procedures such as handwashing and equipment clea-



ning. Studies often point towards microbiological risks posed by this therapy. According to one study, 75% of the sample followed the general nutrition instructions, whereas more than half of it presented inadequate hygiene conditions.<sup>25</sup>

It is essential enabling caregivers to be close to the reference team, given their potentialities and difficulties in the home enteral nutritional care process, as well as the burden of tasks often attributed to these individuals.<sup>2</sup> The significant difficulty associated with patients' diet and with the lack of professional assistance is also added to the higher complication rate linked to the enteral therapy in the group without follow-up, as seen in caregivers' speeches, as well as in the classification of the nature of these complications.

It was like that one time. So, I called SAMU and asked for instructions, they said it could be hypoglycemia, then they came, and they were right. She was hypoglycemic. (Caregiver 4; 27a., without follow-up).

[...] it came back the first time and returned to the lung. [...] I also had difficulties with the probe because it can escape. It escaped several times and she had bronchoaspiration. It was necessary cleaning her lungs because of the diet (Caregiver 8, 34a., without follow-up).

The frequency of complications was higher in this group than in the group followed-up by the nutritionist, if one takes into consideration the same period-of-time, as well as the most frequent mechanical and gastrointestinal complications (Table 2).

**Table 2.** Frequency of HENT-related complications per category in followed-up groups. Foz do Iguaçu County, Paraná State, 2018.

HENT-related complication	With follow-up		Without follow-up	
	n	%	n	%
Mechanical	7	50.00	12	38.71
Metabolic	2	14.29	8	25.81
Gastrointestinal	5	35.71	11	35.48
Total	14	100.00	31	100.00
Total frequency of complications (%)		31,11	68,89	

Source: Prepared by the authors, 2018.

Other studies also reported the incidence of complications at home, mainly of gastrointestinal and mechanical complications after hospital discharge, besides indicating lower survival and high death rates due to malnutrition.<sup>8-9,26</sup>

Challenges arising from adaptations of everyday life to home enteral nutritional therapy, from economic and other difficulties, as well as from coexistence with new conditions such as complications, can contribute to dietary and nutritional insecurity due to inadequate food supply. Consequently, these factors can lead to malnutrition and death.<sup>26</sup>

The current study reported deaths in both groups, although the group without nutritional follow-up recorded death rate two times higher than the one with nutritional follow-up. Differences in nutritional status were also observed in the mean values of each group, based on the standard deviation of body mass index, body fat %, muscle mass, mid-arm muscle and calf circumferences, which were less suitable in the group without follow-up (Table 3).

**Table 3.** Nutritional status of HENT patients with, and without, nutritional follow-up, two weeks after hospital discharge. Foz do Iguaçu County, Paraná State, 2018.

Marker	With follow-up		Without follow-up	
	Mean	SD	Mean	SD
Weight (kg)	61.93	±18.98	46.28	±6.56
BMI (kg/m²)	24.34	±5.32	20.04	±3.70
% Body fat	31.42	±4.82	29.35	±8.16
Mean muscle mass (kg)	41.82	±10.66	32.36	±3.73
MAMC suitability (%)	95.69	±12.85	84.10	±14.00
CC (cm)	28.82	±3.98	25.22	±3.69

Source: Prepared by the authors, 2018.

Four patients presented low body mass index based on calf circumference, which indicated malnutrition in all patients in the group without follow-up; two of them presented severe malnutrition, as seen through their mid-arm muscle circumference, and through their low body fat and lean body mass percentages.

It is worth emphasizing that low calf circumference values are associated with decreased physical capacity, as well as with the risk of fragility and low functional performance.<sup>27,28</sup>

In addition to the mortality rate and to the speeches of caregivers and health professionals about the reduced health evolution pace resulting from lack of nutritional follow-up and multiprofessional teams, these results indicate the importance of having adequate nutritional follow-up after hospital discharge, as well as network reflections.

Patients without nutritional follow-up do not have dietary supervision; consequently, they lose weight and pressure ulcers do not heal. They



stagnate. We can clearly see the color of the wound. It changes everything. (Nurse from the Home Care Program, 62a.).

[...] hence they become increasingly weak. Consequently, they develop other diseases, other complications, and end up dying due to lack of food ... of nutrition. (Nursing Technician from the Home Care Program, 55a.).

Safeness, right? [...] I do not want him to go back to the hospital. [...] (Caregiver 6, 52a., with follow-up).

**“I’m lost!” - The mismanagement of information flows and referrals**

Throughout the current study, participants reported different difficulties and issues that hindered the proper care in HENT. If one takes into consideration the care provided at the primary and tertiary levels by different health professionals whose communication network is weak, it is possible saying that there was no compatibility among the overall home care instructions given by health network teams.

Other authors have also discussed about aspects found in the current study such as difficulty to perform procedures associated with enteral nutrition, financial resources for diets, different and complex guidelines focused on food and nutrition, as well as caregivers’ insecurity and fear to apply enteral nutrition.<sup>9</sup>

Thus, several biological, emotional and socioeconomic complications resulting from home enteral nutritional therapy point towards the need of having local and national organization and legislation focused on standardizing home care services.<sup>9</sup>

The current study also reported communication difficulties among hospital, FHT and FHSC teams, which makes it difficult enabling more objective, interprofessional and inter-sectoral instructions.

[...] each sector discharges the patient. So, they call the nutrition sector, the physical therapy sector and the doctor to discharge the patient. How do we do it together? Even if we have routine .... Then, when patients are discharged, they call the sectors and we have to discharge these patients before they leave. (Nutritionist 6, 36a., Hospital).

This fragmentation in the act of prescribing at hospital discharge can be seen in other studies, which mentioned instructions individually provided by health professionals based on their own perspective about the conduct to be followed and disregarding the importance of an integrated perspective.<sup>29,30</sup>

[...] Then I asked him: Doctor, he's going to be discharged tomorrow, we're worried about the combination between diet and oxygen supply, and about tracheal aspiration, which we are not familiar with ... "No, do not worry, the day he goes home, you will have a nurse and a nutritionist coming along, and they will explain everything once you get home." However, it did not happen. (Caregiver 6, 52a., with follow-up).

[...] sometimes we are informed by patients or caregivers that HCP [Home Care Program] is following-up some patient; that they were not able to communicate with us, or have not tried ... I do not know. And with the hospital: zero communication. I have no contact with them. (Nutritionist 3, 28a., FHSC).

Yet, weaknesses and limitations associated with the lack of experience of most caregivers in HENT operation (n = 10) generated difficulty in preparing the manipulated diet and in applying the enteral nutrition to patients. Consequently, caregivers were insecure about, and afraid of, performing this practice, mainly in the group without nutritional follow-up.

"I'm pretty insecure ... about doing things wrong. Each one explains one thing, and ... I'm dealing with a life, right? So, I think it's pretty, it's ... I don't know. It's pretty hard, you know?" (Caregiver 2, 35a., without follow-up).

AHealth teams should know the family member, or caregiver, in charge of patient's nutritional care in order to better qualify them for this task, as well as to attentively listen to their fears, insecurities and doubts.<sup>2</sup>

[...] I wasn't there on the day she was discharged. My sister-in-law was. That's why I told you: what I'm doing here for her, I learned because of my grandmother [caregiver refers to the home care previously given to her grandmother], [...] Then, on the day she was discharged, nobody knew she was going home that day [...] to my sister-in-law, you know? But, because she was so scared, I think they explained it to her, she just forgot everything [...] (Caregiver 9, 32a., with follow-up).

[...] the nurse and the nutritionist came... just them. [...] one information on top of the other and I did not get it like that. Information was just piling up. Thinking back, we had to split them later. (Caregiver 11, 61a, without follow-up).

Researchers have already reported that only 31.6% of users received reference and



counter-reference instruments such as referrals to primary or home care units. This finding reinforces the need of enabling the effective integration among different health care levels, as well as the need of conducting further studies about the profile of home enteral nutrition in the country.<sup>9</sup> According to Ministry of Health guidelines, nutritional care is part of the integral care in health care networks; thus, it should be associated with different actions in the network in order to qualify and organize the enteral nutrition care process when patients are discharged from hospital and go home.<sup>2</sup>

The enteral nutritional therapy is a complex process that requires collective care; thus, all patients undergoing this intervention should be assisted by a specialized multiprofessional team comprising, at least, the group of professionals proposed by FHSCs in their complete staff. In addition, a family member should accompany the patient during treatment, mainly to report potential HENT-associated issues to the health care team. Users and caregivers should receive a healthcare protocol comprising follow-up instructions in order to be empowered to apply the therapy based on a manual in which each professional involved in the process can communicate relevant subjects to enable satisfactory prognosis.<sup>31</sup>

However, investments in the elaboration of adequate information, and in training health professionals and caregivers, are scarce because, supposedly, there is little time available for this activity. This finding shows the indispensable need of having qualified, and constantly updated, professionals in this Nutrition field.<sup>32</sup>

Another difficulty concerns differences between hospital and home environments, which make it difficult to provide guidance and follow-up. Among the herein investigated cases, one individual from the group without nutritional follow-up and three from the group with nutritional follow-up were visited by FHT professionals (doctor and/or nurse).

This team is in charge of making periodic visits to follow-up individuals undergoing home enteral therapy (more often in the first six months of follow-up), as well as of enabling the communication with different sectors, whenever it is necessary making economic and home adaptations.<sup>2</sup>

Some teams [Family Health Strategy], we know we can ask them. [...] But, the doctor is often the last person going to the patient's home. (Nutritionist 3, FHSC).

So, because we are going, they [the teams] think they don't need to go. But these are their patients, it's their field. (Nurse from the Home Care Program, 62a).

According to the Brazilian Society of Enteral and Parenteral Nutrition,<sup>33</sup> caregivers must feel competent and part of the care process. Thus, it is necessary providing proper training to



them in order to mitigate their fears and insecurities, besides offering assertive and hospital-programmed guidelines that must be corroborated by the health professional teams in contact with the patients after hospital discharge.

Therefore, if on the one hand, there is no professional follow-up due to different issues, even in places where there is human resource for it, on the other hand, it is worth pointing out the lack of human and financial resources due to poor management in the herein investigated county. It makes home enteral therapy, and the expected health evolution of patients, unfeasible due to the discontinuation of follow-ups and to lack of resources to purchase industrialized diets. It is worth emphasizing that the use of alternative food routes, and several dietary restrictions, may affect the routine and life habits of both the patient and his/her family, as well as their social interaction and productive capacity, among other aspects. Therefore, providing care goes beyond the nutritional support; consequently, adopting an interdisciplinary approach is paramount.<sup>2</sup>

The lack of effective communication, flows, among other aspects mentioned in the current study, was significantly influential to the extent that it generated obstacles to the contact between caregivers and nutritionists, even in regions with nutritional follow-up. Besides, there were cases in which users and health professionals were not aware of such possibility.

### **Possibilities of a health care network model focused on enteral nutrition care**

According to health professionals who witnessed the reality of patients with, and without, follow-up and mainly by caregivers who experienced the lack of it, the nutritional follow-up of patients undergoing home enteral nutritional therapy is a need. They also mentioned the need of making investments such as the hiring professionals to form a multiprofessional team (nutritionists, physical therapists and speech therapists), since many patients in the county did not have access to such care. In addition, the follow-up by Family Health Strategy professionals was also requested.

Another aspect mentioned in the current study concerns the provision of industrialized diets developed for enteral therapy, based on the perspective of health professionals and caregivers from both groups. It is worth highlighting that this process is subsidized by a few counties in the country, as well as that the acquisition of dietary supplements is a burden that lies on the patients' family. Such burden compromises domestic budget and jeopardizes the food security and nutrition of the entire family, and violates the Human Right to Adequate Food. This aspect, among others, justifies the urgency of establishing criteria for the supply of this food type.<sup>26</sup>

Participants suggested the standardization of a network protocol focused on organizing the home enteral nutritional therapy in order to help the ones involved in it in order to bet-



ter understand the process, as well as to facilitate the dialogue between professionals, among other aspects. The Ministry of Health recommends elaborating booklets in order to guide the home care process concerning enteral therapy, besides highlighting successful experiences<sup>34-36</sup> with the use of local protocols focused on the priority use of dietary formulas.<sup>2</sup>

In addition, based on a systematic review on home enteral nutritional therapy in Brazil and in the world, with emphasis on the main implications of this therapeutic modality, it was possible observing the lack of universally-accepted protocols for this therapy, as well as the existence of protocols elaborated for certain regions. Such lack of protocols hinders the standardization of the integral care and assistance provided to patients.<sup>7</sup>

The current study did not intend to exhaust the discussion, since further studies about home enteral nutrition<sup>8,9,24,25</sup> should be conducted. On the contrary, it addressed aspects of a situational health condition that requires commitment, humanized care, and the development of a special support network by all professionals involved in the process to enable bonds with caregiving families.

### **FINAL CONSIDERATIONS**

Based on our results, most patients fed on manipulated diets, besides presenting an expressive frequency of complications and less satisfactory anthropometric profile, mainly in the group without nutritional follow-up. Caregivers pointed out the need of providing general, standardized and integrated guidelines focused on the implementation of home enteral nutritional therapy. Health professionals and caregivers pointed out the importance of providing professional follow-up after hospital discharge, as well as of developing a network communication to enable information flows, referrals and follow-up in this therapy, either in hospital or home environments.

The development of a georeferencing program can help locating, and communicating with, health teams and users in the local network to enable the continued care process. In addition, there is the need of developing a national policy focused on regulating, in a more specific way, enteral therapy management guidelines in the counties, since successful experiences are scarce in the national territory.

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### Contributors

Führ AL and Ciacchi EM participated in the study design and development, in data analysis and interpretation, as well as in the writing and final revision of the manuscript.

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