

Home enteral nutrition: profile of users and caregivers and the incidents related to feeding tubes



Nutrição enteral domiciliar: perfil dos usuários e cuidadores e os incidentes relacionados às sondas enterais

Nutrición enteral domiciliar: perfil de los usuarios y cuidadores y los incidentes relacionados a las sondas enterales

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ABSTRACT

Objectives: To characterize the profile of users and caregivers in home enteral nutrition (NED) and to analyze incidents related to enteral probes.

Method: A prospective cohort study with 36 users and their caregivers. Data collection was performed for a period of six months in a home care program at a university hospital. Kaplan-Meier's descriptive analysis and survival curve were adopted.

Results: 66.7% of the subjects were female, 77.8% were aged ≥ 60 years and 88.9% were bedridden. 88.9% of the caregivers belonged to the female sex, had a family bond and age of 51.2 ± 13 years. The incidence of unplanned gastric extubation was 0.67 /100 patient-days.

Conclusions: Despite the scarcity of studies on the quality and safety of home care, actions such as the monitoring of extubations and the implementation of measures that reduce or mitigate such events can contribute to safe and harmless care.

Keywords: Home nursing. Enteral nutrition. Intubation, gastrointestinal. Patient safety. Quality of health care.

RESUMO

Objetivos: Caracterizar o perfil de usuários e cuidadores em nutrição enteral domiciliar (NED) e analisar os incidentes relacionados às sondas enterais.

Método: Estudo de coorte prospectivo realizado com 36 usuários e seus cuidadores. A coleta de dados foi conduzida por um período de seis meses em um programa de assistência domiciliária de um hospital universitário. Adotou-se análise descritiva e curva de sobrevivência de Kaplan-Meier.

Resultados: 66,7% dos sujeitos eram do sexo feminino, 77,8% com idade ≥ 60 anos e 88,9% estavam acamados. 88,9% dos cuidadores pertenciam ao sexo feminino, possuíam vínculo familiar e idade de $51,2 \pm 13$ anos. A incidência de extubação gástrica não planejada foi 0,67/100 pacientes-dia.

Conclusões: Apesar da escassez de estudos na temática de qualidade e segurança em assistência domiciliar, ações como o monitoramento das extubações e a implantação de medidas que reduzam ou mitiguem tais eventos, podem contribuir para assistência segura e livre de danos.

Palavras-chave: Assistência domiciliar. Nutrição enteral. Intubação gastrointestinal. Segurança do paciente. Qualidade da assistência à saúde.

RESUMEN

Objetivos: Caracterizar el perfil de los usuarios y cuidadores en nutrición enteral domiciliar (NED) y analizar los incidentes relacionados con las sondas enterales.

Método: Estudio de cohorte prospectivo realizado con 36 usuarios y sus cuidadores. Se realizó la recolección de datos en un período de seis meses, en un programa de asistencia domiciliar de un hospital universitario. Se adoptó el análisis descriptivo y la curva de supervivencia de Kaplan-Meier.

Resultados: 66,7% de los sujetos eran del sexo femenino, 77,8% con edad ≥ 60 años y 88,9% estaban acamados. El 88,9% de los cuidadores pertenecían al sexo femenino, tenían vínculo familiar y edad de $51,2 \pm 13$ años. La incidencia de extubación gástrica no planificada fue 0,67 / 100 pacientes-día.

Conclusión: A pesar de la escasez de estudios en la temática de calidad y seguridad en asistencia domiciliar, acciones como el monitoreo de las extubaciones y la implantación de medidas que reduzcan o mitiguen tales eventos, pueden contribuir para asistencia segura y libre de daños.

Palabras clave: Atención domiciliar de salud. Nutrición enteral. Intubación gastrointestinal. Seguridad del paciente. Calidad de la atención de salud.

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■ INTRODUCTION

Home care (HC) is seen as a modality of care and is used as a strategy of health organizations, in order to adapt to the change in the profile of chronic-degenerative diseases to the aging population. HC is an alternative for users who are dependent on technological devices, in addition to contributing to a better management of hospital beds, and therefore, the reallocation of health costs. In this sense, the Ordinance No. 825 of April 25, 2016⁽¹⁾ redefines that the HC is aimed at people who are clinically stable, but need health care because they are bedridden and need to be monitored temporarily or permanently, or to those who show some degree of vulnerability. Therefore, home care is considered the best offer for treatment, palliation, rehabilitation and prevention of diseases, with a view to increasing the autonomy of the user, family and caregiver.

One of the assumptions for the HC consolidation is the presence of the caregiver, defined as the a person with or without a family bond, able to care for the user in their daily life needs and activities⁽²⁾. Thus, the role of the caregiver as the subject of the caring process, the active participation of the family and the professionals involved is fundamental in the HC.

HC presents specific challenges regarding patient safety, since the health team is not in a health unit and cannot count on the typical logistics of this service⁽³⁾. In this context, the home enteral nutrition therapy (HENT) is one of the services provided in home care and that can be defined as a method that allows the supply of the nutritional needs of individuals who are unable to guarantee it through oral ingestion⁽⁴⁾.

The home nutritional support has been successful in treating patients who present chronic conditions and who would otherwise need prolonged or repeated hospitalizations to maintain their nutritional needs.

In Brazil⁽⁵⁾, the incidence of HEN is 147.98 million/cases of inhabitants/year and the prevalence of 176.09 million/cases of inhabitants. It should be emphasized that there were no similar investigations in the national territory that portray the prevalence and incidence of HEN in order to allow a comparison between states.

The home gastric intubation is a care practice with the objective of providing nutritional support and drug administration, demanding the installation, maintenance and stability of the tube, administration of the diet and medication, and in the training of the caregivers or the user for the success of the therapy⁽⁶⁾.

Researches have shown that tube-related complications and problems are common with users receiving enteral tube feeding at home, associating them with the care provided. Thus, the need for investigations aimed at assessing the results of the individual's health conditions

is emphasized, as well as on the impact of this care on the quality of life of users and caregivers⁽⁷⁾.

Among the complications involving the gastric tube, there are those of a mechanical nature, such as displacement, the unplanned removal of the catheter, obstructions, disruption of the gastrostomy balloon (GTT), which exposes the user to unnecessary risks, such as bronchoaspiration, discomfort and pain due to reintubations, in addition to long periods of fasting and increased consumption of the material. Regarding the gastrointestinal complications, there are vomiting, diarrhea or constipation⁽⁸⁻⁹⁾.

Thus, complications related to the gastric intubation can be defined as health incidents, which are defined by the World Health Organization⁽¹⁰⁾, as "*an event or circumstance that could have resulted in or resulted in unnecessary harm to the patient*".

A study carried out in Canada⁽¹¹⁾, showed that the rates of adverse events in HC, per user/year were 10.1%, with 56% of avoidable events. The wrong decisions or actions culminated in the occurrence of 48.4% of the events. Of these events, 27.9% resulted from actions of informal caregivers, and 52.6% from users who cared for themselves. It was concluded that the HC contemplates measures of self-care and care provided by formal or informal caregivers, which may influence the occurrence of adverse events, and it is essential to adopt strategies that guarantee a safe care.

Due to the uniqueness of this type of care, the following issues emerged: How does the enteral nutrition therapy occur at home? What is the profile of the users and their caregivers/relatives? What are the main complications of HENT? How has the gastric extubation indicator been monitored in home care?

Based on these questions, the present study aimed at analyzing the incidents related to enteral feeding tubes and to characterize the profile of users and caregivers in HEN in a home care program of a university hospital in the city of São Paulo.

■ METHOD

This is a prospective cohort study with survival analysis from the *Kaplan-Meier's* curve from a thesis⁽¹²⁾. The population consisted of all users in home enteral nutrition therapy, independently of the gastric intubation route, and their respective caregivers, inserted in a home care program of a university hospital in the city of São Paulo. The following exclusion criteria were established: death within the first 24 hours after hospital discharge or feeding exclusively by oral route. Thus, the population was composed of 36 users and 36 caregivers. The data collection occurred between October 2015 and March 2016. All users are monitored ac-

cording to their clinical complexity, ranging from weekly to monthly visits. All caregivers are advised about care, including handling and administration of the diet, at the first home visit by health care professionals.

The data collection was done from two instruments, the first one divided into two parts. In the first part, there are sociodemographic and clinical data; and in the second part of the instrument, the data related to the gastric extubation incident and the reasons involved were considered. The dependence degree was calculated by applying the Katz index⁽¹³⁾, in the version of *The Hartford Institute for Geriatric Nursing*. This index is based on the assessment of the Basic Activities of Daily Living (BADL) and measures the functional capacity of the individual from six activities: bathing, dressing, going to the bathroom, transferring, having urinary and fecal continence and eating. Each activity is rated as zero score or one, where one represents total independence. Thus, after the summation, the individual who reaches six points is classified as independent, four points partially dependent and two points or less, totally dependent. The second instrument aimed to measure the total number of day-patients submitted to gastric intubation.

The responsible researcher made the first telephone contact with all the caregivers/responsible for the eligible users, explaining the objectives and the need to consult the data of the medical record. On the occasion of the home visit, the terms of consents were obtained, and then the forms were filled weekly by the researcher in the home care program.

The data was organized in a spreadsheet in *Excel for Windows*® and analyzed by the *software Stata*® version 13.0. For the qualitative variables, the relative and absolute frequencies of the classes of each variable were used. For the quantitative variables, the averages and medians, standard deviations, minimum and maximum amplitude were used to indicate the variability of the data. In order to compare the variables of the extubation types as a function of the retention time, the Chi-Square and Student's T were applied. The level of significance adopted was 5%. The *Kaplan-Meier's* survival curve was used to analyze the feeding tube retention time, that is, from the moment the feeding tube is introduced until its extubation. In this study, the retention time between extubation types was also compared: planned and unplanned. In order to calculate the rate of incidents related to the gastric intubation, the following indicators were calculated:

Incidence of gastric extubation = $\frac{\text{No. of gastric extubation}}{\text{Total day-patients with gastric intubation}} \times 100$

Incidence of planned gastric

extubation = $\frac{\text{No. of planned gastric extubation}}{\text{Total day-patients with gastric intubation}} \times 100$

Incidence of unplanned gastric

extubation = $\frac{\text{No. of unplanned gastric extubation}}{\text{Total day-patients with gastric intubation}} \times 100$

The planned extubation was characterized by the end of the therapy, by the elective replacement of the tube (according to institutional protocol, every 6 months) or alteration of the intubation route (nasogastric for gastrostomy); the unplanned was characterized by the removal of the tube by rupture of the balloon, by obstruction, by deterioration of the material, by the selective position or withdrawal of the tube inadvertently by the user, health professional or caregiver/family member.

The following terms have been elaborated: Free and Informed Consent Form (FICT), Authorization Term for Data Collection of the Record and the Assent Term. All the documents were prepared in two copies, one of them was handed to the participant, and the second one remained with the researcher. All the participants were informed about the objectives of this investigation.

This research was carried out after the approval of the Research Ethics Committees of the School of Nursing of the University of São Paulo (EEUSP) and the hospital, under CAAE 45534015.2.0000.5392, and opinions 1,180,578 3 and 1,194,181, respectively .

■ RESULTS

Through the analysis of the data in Table 1, it was observed that women predominated (66.7%) and that most subjects (77.8%) were aged ≥ 60 years old. The age corresponded to 66 ± 26 years old, ranging from 6 to 92 years old.

Concerning the admission diagnosis, most of the users presented neurological disorders, represented by stroke sequelae (52.8%) and other neurological syndromes (25%).

Table 2 shows that, in relation to the degree of kinship and schooling, the majority (88.9%) was a relative, (41.7%) represented by the child and 44.4% finished high school.

In relation to the characteristics of HEN, regarding the access route and type of diet, of the 36 users, there was a predominance of the nasoenteral route (52.8%) and the type of diet, industrialized (47.3%), with lower percentage of the artisanal diet (19.4%).

Table 1 – Distribution of sociodemographic and clinical characteristics of users in HENT, São Paulo/SP. n=36 users

Variables	N	(%)
Gender		
Female	24	66.7
Male	12	33.3
Age group		
< 18 years old	5	13.9
18 -- 60 years old	3	8.3
≥ a 60 years old	28	77.8
Main Diagnosis		
Stroke sequelae	19	52.8
Neurological Syndromes	9	25
Dementias	7	19.4
Neoplasms	1	2.8
Katz Index		
Totally dependent	32	88.9
Partially dependent	3	8.3
Independent	1	2.8
Mobility		
Bedridden	32	88.9
Moves with aid	4	11.1
Moves by themselves	0	0
Home		
Adequate	24	66.7
Inadequate	12	33.3

Source: Research data, 2016.

Regarding the occurrence of incidents with the feeding tubes, the greatest percentage (58%) was the unplanned extubation. The planned extubations (42%) included the elective replacements, which occur every 6 months, according to the institutional protocol or chan-

Table 2 – Distribution of socio-demographic characteristics of the caregivers. São Paulo/SP. n=36 users

Variables	N	(%)
Gender		
Female	32	88.9
Male	4	11.1
Age group		
20 -- 40 years old	7	19.4
41 -- 59 years old	21	58.3
≥ a 60 years old	8	22.3
Connection		
Relative	32	88.9
Not a family member	4	11.1
Kinship*		
Daughter/Son	15	41.7
Spouse	6	16.6
Mother	5	13.9
Siblings	5	13.9
Grandchild	1	2.7
Schooling**		
Complete High School	16	44.4
Incomplete Elementary School	8	22.2
Complete Elementary School	5	13.9
Complete Higher Education	5	13.9
Incomplete High School	1	2.8

Source: Research data, 2016

* four caregivers did not have a family connection

** one caregiver did not report their schooling

ge of feeding route, that is, from the feeding tube to the oral route.

The findings of Table 3 depict the prevalence of unplanned extubation in users whose route was by the nasenteral tube 16 (57.2%).

Table 3 – Distribution of the reasons for unplanned extubation according to the type of catheter. São Paulo/SP. n=28 unplanned extubations

Reasons	Type of catheter					
	GTT		SNE		TOTAL	
	n	%	n	%	n	%
Balloon rupture	9	32.1	0	0	9	32.1
Removal by the patient	0	0	6	21.5	6	21.5
Selective position of the tube	0	0	6	21.5	6	21.5
Inadequate fixing	0	0	2	7.1	2	7.1
Obstruction	0	0	2	7.1	2	7.1
Access Deterioration	2	7.1	0	0	2	7.1
Removal in the procedure (bath)	1	3.6	0	0	1	3.6
Total	12	42.8	16	57.2	28	100

Source: Research data, 2016

The incidence of extubation is considered as an indicator of the quality and safety of care, so it deserves to be monitored, having its oscillations and trends analyzed, in order to implement actions aimed at con-

tinuous improvement, and for reducing the risks arising from this therapy.

Thus, the calculation of incidence rates of planned and unplanned extubations is shown in Table 4.

Table 4 – Distribution of the incidence of planned and unplanned extubation of the gastric tube for nutritional support. São Paulo/SP. n=48 extubations

Month	Type		TOTAL
	Planned n=20	Unplanned n=28	
1	0.30	0.75	1.05
2	0.14	0.74	0.89
3	0.57	0.57	1.14
4	0.69	0.41	1.10
5	0.46	0.62	1.08
6	0.67	0.93	1.60
Total	0.48	0.67	1.15

Source: Research data, 2016

During the 6 months, there were 48 extubations in 4154 days of intubated users; the overall incidence was 1.15 per 100 patients per day, 0.67 for unplanned and 0.48 for planned. The incidence in the period was 1.14 ± 0.23 . In the third month of study, there was no difference in number between extubations.

Figure 1 shows that the probability of tube retention in the first month for unplanned extubation was 62.5%. In the fourth month, it increased to 37.5%; and in 6 months to 6.25%. For planned extubation, the probability of tube retention at the end of the first month was greater than 88%; and in 6 months, it was 55.5%.

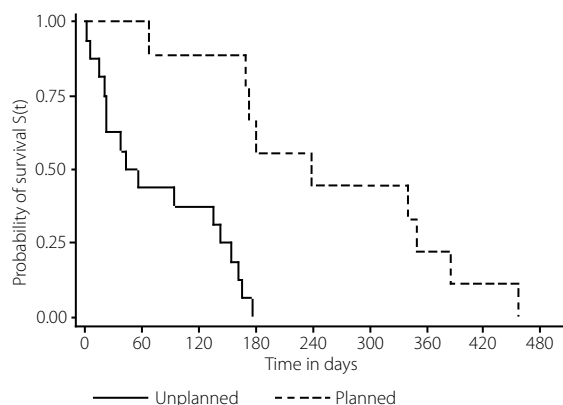


Figure 1 – Probability of tube retention. São Paulo/SP - 2016

Source: Research data, 2016
Chi-square Test, $p=0.001$

Regarding the survival time of planned and unplanned extubations, the data revealed statistically significant differences, indicating that the unplanned occurred much earlier than planned ($p=0.001$).

Regarding the tube retention time, from the insertion to the occurrence of the first event, as the first extubation, the average tube retention time for planned extubation corresponded to 68 days, and for the unplanned time, 35 days.

When comparing the average time between the planned and unplanned extubations, when applying the *t-Student's* test, there was a statistically significant difference ($p=0.007$) between the types of extubations, being significantly higher for the planned extubations.

■ DISCUSSION

In this study, it was sought to analyze incidents related to enteral feeding tubes, and to characterize the profile of users and caregivers in HEN in a home care program.

It was verified that the profile of the users is characterized, for the most part, by the female gender, aged ≥ 60 years old, having as main diagnosis, the neurological diseases.

Similar results regarding gender and age; 51.4% were women and 67.6% were in the age range ≥ 60 were found in a study conducted in the same service⁽¹⁴⁾.

A study carried out in a city of Minas Gerais⁽¹⁵⁾, with HEN users, the majority (52.6%) were females and the average age was 67.5 years old, and the main diagnosis (63%) consisted of neurological diseases.

Still in Brazil, it was found 50% female, 64.6±18,6 years old, and 69% were over 60 years old⁽¹⁶⁾.

A multicenter study in Spain⁽¹⁷⁾, showed that neurological disorders were the main diagnoses, both in the pediatric group, represented by neurological syndromes (49.1%) and in 60.6% in the adult group.

In a recent research⁽¹⁸⁾, it was found that among the HEN users, the majority were women (59.7%), with an average age of 79 years old, and the percentage of users above 65 years old was 78.6%. Regarding the diagnosis, 51.7% of the users had neurological disorders.

Thus, the findings of the present study converged with those found in the national and international literature regarding the gender, which is predominantly female, aged over 60 years old, and most users have a main diagnosis of neurological disorders.

The dependence degree of the individual can be influenced by the aging process, by the chronic-degenerative diseases, causing functional losses that compromise the basic daily living activities, among them the ability to dress and feed themselves.

Regarding the dependence degree, most of the subjects were totally dependent on the daily living activities, and in relation to mobility, the majority were composed of bedridden individuals. The degree of dependence is variable, as pointed out in the study⁽¹⁹⁾, which used the Katz index, demonstrating that 100% of the HC service users had the degree of total dependence.

Still, in the international literature, 56.5% of users were totally dependent on care; and in relation to mobility, 49.4% of the users needed help to move from the bed to the chair⁽¹⁷⁾. Thus, based on findings in the literature, the majority of HC users present limitations regarding autonomy and mobility, corroborating the data obtained in the present study.

Regarding the housing conditions, the majority of the residences of the users presented minimum conditions for the establishment of the HC. It was also verified that structural and sanitary adjustments are necessary, such as water, sewage and physical plant to improve the quality and safety of home care.

Over six months, over half of the users remained in HC; the reasons found for those who left the service were death, clinical improvement and change of address.

A study carried out at the same service in 2010⁽¹⁴⁾ pointed out that 56.8% of users remained in HC; regarding the reasons for discharge, the majority (69%) evolved to death. When comparing the reasons for the discontinuation of the present investigation with these findings, a reduction in the reason for discharge from HCP due to death was

observed. A study carried out in Spain mentioned death as the main reason (29.3%) for the HEN service discharge, followed by 17.1% for the clinical improvement⁽¹⁷⁾.

The HEN requires special care, which must be performed by the caregiver/family member indicated and properly advised by health professionals, involving the preparation and administration of diet, medication, fixation and handling of the feeding tube. The caregiver is the person who, in the private domestic space, performs or assists the person with limitation to do their basic and instrumental activities of daily living, with the aim of preserving their autonomy and independence⁽²⁾.

The findings of this study corroborate similar studies, in which the majority of the caregivers were female, were in the age group between 18 and 60 years old; with an average age of 50.6±13,4 years old. Regarding the caregiver's relationship with the user, 97.3% were family members; being 27% represented by the mother and 21.6% by the son or daughter⁽¹⁴⁾.

Recent data⁽¹⁸⁾ demonstrated that female caregivers were four times greater than males, aged 53.1±13,4 years old and the family bond of child (50%), followed by wife/husband (16%).

In a study conducted in Brazil⁽¹⁵⁾, the predominant access route to HEN corresponded to the nasoenteral tube, used by 63% of the users, followed by the nasogastric tube (21%) and GTT (16%). Regarding the diet type, 52.6% of the individuals received industrialized formulas, followed by 42.1% of mixed diet (semi-artisanal)⁽¹⁵⁾. A similar study⁽¹⁶⁾, also pointed out the most used access route to GTT (52.4%) and the nasogastric/enteral route corresponded to 33.3%. As for diet type, 57.1% received a mixed diet (semi-artisanal) and 23.8% received an industrialized diet.

When comparing the findings of this study, with the study carried out in the same service in 2010⁽¹⁴⁾, only 2.7% of the users received an industrialized diet and 51.4%, the semi-artisanal, evidencing an expressive increase of users making use of the industrialized diet.

Regarding the occurrence of unplanned extubations, in the same HC program⁽¹⁴⁾, it was found that the percentage of this incident was 75.9%. Therefore, a reduction in the percentage of this event was verified.

Incidents related to HEN, specifically extubations, can result in unnecessary harm to the user, such as clinical instability, exposure to an invasive procedure, pain, and other consequences of such an event. However, there is a shortage of articles in the literature monitoring the incidence, reasons, or circumstances involved in these events, as well as the consequences of unplanned extubations.

In a study conducted in the Intensive Care Unit (ICU) and Medical Clinic⁽²⁰⁾, the authors verified that, during 5

months, measuring the inadvertent output of the gastric tube for nutritional intake, 75% of the subjects had extubation, 10% had two extubations, and 10% had seven extubations; those whose extubations were greater than six, were conscious and agitated, being necessary the mechanical containment in bed.

A research conducted in 2010⁽¹⁴⁾, found that 34.5% of the unplanned extubations were due to the balloon rupture of the GTT users, followed by 20.7% of spontaneous removal by the patient, in the SNE patients.

Still in the international literature, authors have found as reasons for the unplanned removal, the break and occlusion of the tube⁽⁷⁾, and detected as a more frequent complication the inadvertent tube removal (45.1%). In a study conducted in the same service⁽¹⁴⁾, the overall incidence of extubation was 1.06/100 day-patients, of which 0.80 were unplanned and 0.26 were planned. When comparing the results of the present investigation, using the same methodology, it was verified that there was no significant increase of the general incidence and a slight decrease of the unplanned one.

A study carried out in a general ICU, aiming at correlating the nursing team dimensioning and the quality indicators of care, found that, in 2008, the average of inadvertent SNE removal for nutritional intake was 2.33 ± 1.51 and, in 2009, 2.53 ± 1.79 ⁽²¹⁾.

Analyzing the feeding tubes survival time, a study performed at the same HC service in 2010⁽¹⁴⁾, demonstrated that in the first month, for unplanned extubation, the probability of permanence corresponded to 59.1% and 57.1% for planned extubation.

Thus, from the findings in this study, it was verified that there was an increase in the probability of the feeding tube permanence, at the end of the first month, for planned and unplanned extubations.

■ CONCLUSIONS

The profile of the users of this study presented characteristics of a population that is mostly elderly, and in chronic health conditions consonant the results of the literature. The caregiver/family member is an essential element for the establishment of the home care. Thus, this person is presented as a component that can influence the occurrence of incidents and/or adverse events in HC, since they are responsible for the maintenance of the feeding tube, preparation and infusion of the diet and administration of the medications. The incidence rates of unplanned extubation presented lower indexes when compared to a similar study performed in the same service, and the increased

use of the industrialized diet. However, half of the users do not have this option, setting up an opportunity for discussing the diet acquisition and dispensing process.

HC is a complex care modality, which presents several elements that need to be studied and analyzed in order to guarantee the quality of the care and patient safety. It is considered a limiting factor for this study the lack of publications related to quality and safety in HC, specifically the monitoring of the gastric extubation indicator, making it impossible to compare the results.

However, the results of this study contribute to teaching and research in health, due to the lack of publications in the area. In addition, the characterization of the users in HEN and their respective caregivers, besides the monitoring of the extubations through the use of indicators, allow implementing measures that can reduce such incidents, contributing to a safe and harmless care.

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