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ORIGINAL ARTICLE

PERCEPTION OF CAREGIVERS ABOUT THE ASSISTANCE TO PATIENTS UNDER HOUSEHOLD ENTERAL NUTRITION

PERCEPÇÃO DE CUIDADORES SOBRE A ASSISTÊNCIA A PACIENTES EM NUTRIÇÃO ENTERAL NO ÂMBITO DOMICILIAR

LA PERCEPCIÓN DE LOS CUIDADORES ACERCA DE LA ASISTENCIA A PACIENTES BAJO NUTRICIÓN ENTERAL EN SU DOMICILIO

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ABSTRACT

Objective: to recognize the difficulties coped by caregivers of patients using enteral probe for feeding. **Method:** it is a descriptive-exploratory study of a qualitative approach with a phenomenological approach. Participants were seven caregivers of patients with enteral probe, interviewed from a semi-structured script, videotaped for later description, reduction and understanding from the obtained reports and construction of the categories. **Results:** from the reports three categories emerged: << Difficulties in the manipulation and maintenance of the probe >>, << Opinion about the received guidelines >> and << Better at Home Program Assistance >>. It has been observed that the needs for enteral probing are personal and related to their life experiences. **Conclusion:** for the relatives, the return of the person to home is very joyful, but followed by the feeling of anguish and stress. This study may help health professionals rethink their practices in the care of enteral probe users. **Descriptors:** Enteral Nutrition; Family; Nursing Care; Qualitative Research.

RESUMO

Objetivo: conhecer as dificuldades enfrentadas por cuidadores de pacientes em uso de sonda enteral para alimentação. **Método:** estudo descritivo-exploratório de abordagem qualitativa com abordagem fenomenológica. Os participantes foram sete cuidadores de pacientes com sonda enteral, entrevistados a partir de um roteiro semiestruturado, vídeo-gravados para posterior descrição, redução e compreensão dos relatos obtidos e construção das categorias. **Resultados:** a partir dos relatos emergiram três categorias: << Dificuldades na manipulação e manutenção da sonda >>, << Opinião quanto às orientações recebidas >> e << Assistência do programa Melhor em Casa >>. Observou-se que as necessidades de sondagem enteral são pessoais e relacionadas às suas experiências de vida. **Conclusão:** para os familiares, a volta do ente para a casa é de muita alegria, porém, acompanhada do sentimento de angústia e de estresse. Este estudo pode auxiliar profissionais da área da saúde a repensarem suas práticas no atendimento aos usuários de sondas enterais. **Descritores:** Nutrição Enteral; Família; Cuidados de Enfermagem; Pesquisa Qualitativa.

RESUMEN

Objetivo: conocer las dificultades que enfrentan los cuidadores de los pacientes en el uso de la sonda de alimentación enteral. **Método:** se trata de un estudio descriptivo de enfoque cualitativo con un enfoque fenomenológico. Los participantes fueron siete los cuidadores de pacientes con tubos de alimentación enteral, los encuestados de un guión semi-estructurado, grabados en vídeo para la descripción más adelante, la reducción y la comprensión de los informes obtenidos y la construcción de las categorías. **Resultados:** a partir de los informes emergieron tres categorías: << Las dificultades en el manejo y mantenimiento de la sonda >>, << Opinión acerca de las orientaciones recibidas >> y << El Programa de Asistencia Mejor en Casa >>. Se observó que las necesidades de sonda enteral son personales y en relación con sus experiencias de vida. **Conclusión:** para la familia, el regreso de las personas a la casa es una gran cantidad de alegría, sin embargo, acompañado de la sensación de ansiedad y estrés. Este estudio puede ayudar a los profesionales de la salud para modificar sus sistemas de servicio a los usuarios de sondas enterales. **Descriptor:** Nutrición Enteral; Familia; Atención de Enfermería; Investigación Cualitativa.

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INTRODUCTION

Food is where we produce the necessary nutrients that provide essential energy for the growth and survival of living beings, as well as it is a physiological need. Enteral nutrition (NE - in Portuguese) is one of the resources that man uses to maintain life in a patient with some change in the physiological process of feeding and it is an important part of nutritional support, manifested through the continuous activity of the organism, including metabolism, growth, reproduction, and existence.¹

The provision of probe feeding techniques is used in cases where patients have functional limitations for oral food intake, such as in neurological changes or after extensive head and neck surgeries.²⁻³ The introduction of the enteral probe and the verification of its position are of the responsibility of the nurse.⁴ The procedures related to the administration of nutrients through enteral nutrition provided at the patient's home with the purpose of improving or keeping the nutritional status are defined as Home Enteral Nutritional Therapy (TNED - in Portuguese).⁵

The relatives of the patients under this condition are of great importance, since they play a vital role in the care under Enteral Nutrition (NE) and, especially, in the administration of nutrition. When properly trained and prepared to assist those patients, they feel familiar and develop effective care.⁶

The family, the caregiver and the patient should be advised about the use of enteral feeding, its risks and benefits. The nursing team has an important role in assisting patients under the use of an enteral probe through emotional support aimed at minimizing fears and apprehensions. Nursing and nutritional guidelines should be verbally and written.

Most enteral nutrition is unwanted, but imposed, and this affectively represents a social untying, generating stress for the patient and his families. It should also be considered that meals are always offered at the same time, which leads to the monotony of food and also to impaired self-image; it can interfere with the sociability and inactivity of the patient, causing anxiety and depression.¹

Family and caregivers report that caring for someone with an enteral feeding probe raises feelings of insecurity, fear and nervousness. Caregiving makes the family member responsible for it and usually it is the task of a single family member, which adds up to the

other activities. Suffering and anguish at seeing someone in the family under such an uncomfortable situation generates a great emotional weight. It is also highlighted the wear caused by care, which does not positively affect the patient, the caregiver and the family.⁸⁻⁹

In view of this, the present research aims to recognize the difficulties faced by caregivers of patients using enteral feeding probe.

METHOD

It is a descriptive-exploratory study of a qualitative approach, held in Montes Claros (MG), Brazil, in the period from April to May 2015. Participants were seven caregivers responsible for assisting patients receiving enteral diet. There were adopted the following inclusion criteria: caregivers, over 18 years old, of patients who made use of enteral nutrition through Nasoenteral Probe (SNE) or Oroenteral Probe (SOE), in home environment. This number was defined by theoretical saturation of data, that is, knowledge of the researcher about his subject of study that allows him to understand the range of his object, when the volume of information collected is sufficient to explain the subject.¹⁰ There were excluded from the research the study subjects who did not accept to participate in the research or who were not found at home after three trials.

In order to recognize the perception of the caregivers with respect to the proposed theme, the theoretical reference of the Phenomenology was used, and the following guiding questions were adopted: "Tell me about what it is like to take care of the person with a feeding probe" and "What is your opinion with respect to the guidelines received for patient care?" This reference was chosen because it is a method that looks for the interpretation of the world through the subject's consciousness formulated based on his experiences. It is necessary to recourse to discourse, to description, to the approximation of the semantic density of the human phenomenon.¹¹⁻² The Phenomenological Research starts from the understanding of living focused on the meanings of perceiving.

After the authorization of the Municipal Health Department of Montes Claros-MG for the accomplishment of the research, information regarding the name, telephone and address of the patients in use of SNE and SOE were collected together with the Best at Home Program of Montes Claros to obtain a name, telephone and address of participants.

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Initially, the moderator thanked the participants for their presence, preceded the members' of the group introduction and presented them the study objectives. Then the reading of the Informed Consent was conducted and the formalized consent of the participants in the research through their signature. For the participants who could not sign the name there was performed the collection of their digital.

The researchers presented themselves to the participants, explained the purpose of the study and requested their consent for the research through the Informed Consent Term.

The testimonials were videotaped by a mobile device model L1 LG™. The transcript of the speeches of the participants and the analysis of phenomenological study followed the steps of description, reduction and understanding.¹³ Later, reading and re-reading the reflective transcripts; extraction of interpretative pieces; implementation of categories and reorganization.

Each participant was represented by the letter E (interviewed) followed by numbers related to the interviews, assuring them, so, the secrecy of their identities.

The research had the project approved by the Research Ethics Committee of SOEBRAS under the Opinion Paragraph Nº 987,381 embodied in 2015 and obeyed the ethical precepts of Resolution 466 / 2012 of the National Health Council.

RESULTS AND DISCUSSION

There were interviewed seven caregivers responsible for the care of patients receiving alternative enteral diet (SNE / SOE). Of these, five were family members of the patient. All the interviewees were female.

In the analysis of the discourse about the perceptions of family members and caregivers about the care of patients receiving enteral diet by alternative route and regarding the orientation received, there were revealed three categories: "Difficulties in the manipulation and maintenance of the probe", "Opinion about guidelines received" and "Better at Home Program Assistance".

♦ Difficulties in the manipulation and maintenance of the probe

This category refers to the difficulties presented by the interviewees in the manipulation/ maintenance of enteral feeding probe. The obstruction was the greatest difficulty perceived, evidenced in the lines of respondents: E2; E4; E5 and E7.

Hard [...] how to unclog [...] for the food don't do clog the probe (E2).

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It is very difficult, [...] when clogs, [...] we have to call the best at home to come and help to remove [...], depending on the food clogs that you can't unclog (E4).

Look at the beginning was very difficult [...], I didn't know how to make stasis [...], in the case of the probe clog, [...], she pull the probe then I get desperate (E5).

In the early days, sometimes the probe got clogged and we didn't know unclog (E7).

Other difficulties encountered by respondents were related to the administration of medication and diet, difficulties about how to act in front of episode of gastric stasis.

[...] at first, I had a lot of difficulty in administering medications, the proper diet [...] (E1).

Difficult [...] 'to apply' the medicine in the probe [...] (E2)

Look, I find it difficult, [...], I'm always with the foot behind miss something, [...]. It was getting dark, so we are left with doubt, huh, when you return the probe? (E3).

The administration of the enteral diet is done by means of a syringe or equipment that connects the diet to the probe, with the sedated patient or with the raised head. Thus, it is possible to provide the nutrients that the person needs regardless of his co-operation, hunger, or the urge to eat.¹⁴ It is important to give preference to liquid medicines, or when this is not possible, tablets or water pills should be dissolved in water, injecting into the probe.⁹

The obstruction may have the possible causes of inadequate washing of the probe and medications adhered to the probe.⁹ The care to avoid probe obstruction is the hygiene of the it with 10 ml of filtered water, at least at the end of each diet, after aspiration of gastric contents and after administration of drugs, in order to avoid accumulation of residues and formation of crusts. The author also emphasizes the importance of care with SOE / SNG; such as: avoiding traction, displacement out of the stomach or intestine and accidental withdrawal, since it is known that performing the probe introduction procedure causes discomfort to the patient.¹

The administration of diet by probe requires knowledge about the care with its maintenance and possible complications that may occur during its infusion. It is recommended that this technique be supervised by a nurse.¹⁵

♦ Opinion about guidelines received

This second category demonstrates the opinion of the interviewees regarding the orientations that they obtained before the

implantation of the enteral probe. It is the nurse who often directs care about positioning, teaches how to manage diets and care during and after administration. This professional provides information about the necessary equipment, purchase and storage of the formula and administrations.¹⁶

Explaining and guiding the patient and the caregiver about the importance and the need of the use of the probe is indispensable for the procedure to be easier later.¹⁷ Based on the interviews conducted, five of the interviewees stated that they had received guidance and clarification, demonstrated in the statements of the interviewees E1; E2; E3; E5 and E7.

[...] It was very quiet, I was well educated, taught me how to do it right. The difficulties, the doubts that I had I got at the hospital even [...] (E1).

Was too good, [...] because the elderly person for us to take care of him you have to be extra careful right, then how much more is a nurse, someone teaches us, is best [...] (E2).

[...] within the guidelines that we received, we seek the way it receives [...], so far I believe that a happened nothing wrong [...] (E3).

Very good guidelines that gave me really helped take care of her (E5).

All very enlightening [...], they guide the way so that we can understand everything.

Very well explained [...] (E7).

E4 and E6 respondents claim that the guidelines were not satisfactory or not received, as exposed in the lines:

The guidelines of the hospital were not so clear, not us, we had a lot of difficulty because of the guidelines. [...] Because they didn't explain how much dosage of water that has to put the probe, and not the other, the foods that do not look like they could be administered (E4).

Oh, I didn't have much guidance about the probe [...] (E6).

The caregiver/family member needs to be guided about how to act in different situations that may arise and also underscores the need for a follow-up of the health service.⁸

It is of the utmost importance that all nursing professionals to be trained to act and provide care and not only specific information about enteral nutrition, but in general. Because the nursing staff plays a key role in developing, since maintenance and control actions, choice and the volume administered, to the most varied reactions the patient under the use of enteral probe can present.¹⁸

◆ Better at Home Program Assistance

In this category, the importance of the Better at Home Program Assistance for these families is evident. This program assists people in need of motor rehabilitation, the elderly, chronic patients without aggravation or in a post-surgical situation, for example, receiving free multiprofessional assistance in their homes, with care closer to the family. The team is formed primarily by doctors, nurses, nursing technicians and physiotherapists. Other professionals (speech therapist, nutritionist, dentist, psychologist and pharmacist) may be part of the support teams.¹⁹

The importance of the program to these families is evident in the testimonies of the interviewees, who explain how much they need support so that they can solve all doubts regarding decision making regarding patient care.

It is very important because it has nursing, doctor, physiotherapist, psychologist, nutritionist and academic support, so it is very good for us because we can always be in doubt; they are teaching us a new way of being caring for them.] (E1).

The young man is too good, [...] the person guides us, [...] we learn more, right, [...] then the more someone teaches us, the better it is for us to be more up-to-date in the area (E2).

Look, although we do not have the presence every day, more to me is great, why sometimes we do not have the presence of other days, anything else that we ... any difficulty that people call them on time as soon as possible (E3).

The best at home is very good, it helps us a lot, a matter of prescription, medicine, teaches also to take care, [...], taught to do everything with the probe, until feeding they gave us to do with it was better than the of the hospital [...] (E4).

Look, they (Better at Home) help us a lot, especially when she has a fever, then I do not know, they come and help me until I take a shower, they already helped me right here, [...] (E5).

Look, it was good because they explain me so; [...], here the girls told me that when I came out, I let them go or they blocked me to call them, so it was very good (E6) .

The program is very good, very good, they are present, every day come, when we need can be whatever time we call, they are willing is very good (E7).

The Better at Home teams are hired by states and municipalities. The service to the population is made during the whole week, 12 hours a day and on duty, on weekends and holidays.¹⁸

All patients receive regular team visits and are monitored. Depending on the clinical status and evaluation of each patient, the number of visits to each patient is defined. The caregiver is anyone who may or may not be a family member who will be the reference of the family to the Better at Home teams.

CONCLUSION

The caregiver profile represents an individual who is not necessarily related to the health service, often without guidance and destitute of professional health support. In caring for people with enteral probe, family/caregivers play a vital role. So the ongoing training and support of those caregivers is critical. It is particularly important and necessary the extension of actions that have the caregiver as the dominant subject, so that this activity is recognized and involved in appropriate practices, bringing benefits to those who care and who is cared for.

The results of the research mention the difficulties that each caregiver/family member presented, being the obstruction of the probe the main difficulty exposed by them. In this context, the service provided by professionals of the best in the home of this city, assumes the role of a great ally of families for problem solving and providing information for the best care of the patient. In this study, the instability in the guidelines provided in the institutions that promote the insertion of the enteric probe is highlighted.

To conclude, the caregivers/family have a vital role in the care of patients with enteral diet by probe. The health education tool, developed mainly by the nursing team in the care of those patients, it should be carried out with responsibility, competence and efficacy to ensure continuity in home care and to improve the quality of life of those patients.

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