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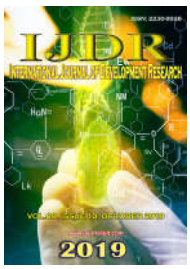

RESEARCH ARTICLE OPEN ACCESS

CAREGIVER'S PERCEPTION OF GASTRO-GASTRIC PATIENTS REGARDING HOME CARE

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ABSTRACT

The objective of the study was to identify the perception of caregivers of gastro-gastric patients regarding the preparation for home care. This is an exploratory / descriptive study, structured from a qualitative and field research conducted in Santa Maria - RS, with caregivers of patients who have endoscopic gastrostomy and who provide home care. Data collection was performed from March to April 2018, until their saturation, ten participants underwent semi-structured interview, data analysis followed the criteria proposed by Bardin. From the data analysis, two categories emerged, namely: Difficulties in home care after endoscopic gastrostomy; and follow up after endoscopic gastrostomy. Caregivers have concerns and fears about the proper care of gastro-patients, this deficit appears in the daily techniques and handling of the tube. It was evidenced that the participants did not receive written instructions or any post-procedure follow-up, which contributed to caregivers' fear, indicating weaknesses in care. There was a gap in the production of knowledge about the present theme, it is suggested to expand studies and research in order to ensure the improvement of quality of life of these patients.

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INTRODUCTION

Endoscopic procedures have shown increasing evolution due to the technical development of the equipment and the expertise of the specialists, allowing the execution of increasingly less invasive procedures, benefiting patients. One of these procedures is the Percutaneous Endoscopic Gastrostomy (GEP). Endoscopic gastrostomy is usually indicated for decompression of the digestive tract or food support for more than 30 days. It is indicated because it is more comfortable and allows greater mobility for the patient (Souza, 2016 and Oliveira, 2016). Length of stay with GEPé, undetermined , it may be months or years, and in some cases it is not possible for the patient to have oral feeding again, making use of GEP permanently, as in cases of Alzheimer's or neurological diseases without recovery (Yamamoto, 2014). Effectively managing nutrients via the enteral or parenteral route is now considered a safe and widely used form of nutrition, especially in patients who need to correct their nutrient deficit and who have an inability or inability to do so orally. From this perspective, GEP becomes an alternative nutritional route (Nascimento, 2015).

The presence of this device implies continuous professional monitoring, requiring adjustments to the limitations imposed on the patient. In this context, the role of the nurse is highlighted, giving confidence and safety to patients and their caregivers. This professional should be prepared to interact with the family and caregivers, establishing a collaborative and respectful relationship.3 puncture site, local infection and pain, early catheter removal and gastrococutaneous fistula, these complications are subject to intervention by the nursing staff (Yamamoto, 2014). Favorable results are known when recommendations regarding the care of insertion, management and removal of the GEP catheter are given by qualified professionals prepared to answer any questions these caregivers have about the patient's new routine. These recommendations reduce the complication rate. and assist in rehabilitation4. Therefore, nursing care is essential for patients, caregivers and family members, since GEP requires specific care and guidance, from hospitalization to home. The systematization of this care by nurses requires organization, evaluation and planning, along with others involved in this process (Oliveira, 2016). Currently, there is an increase in the

performance of GEP in an outpatient setting, ie, the patient performs the procedure in a specialized clinic, is under observation, and is released to their residence with their caregivers or family. It is at this time that changes in care are observed, as patients and caregivers are faced with a new reality. Thus, attention to the patient and caregiver through proper guidance is essential for the success and adaptation of the GEP in order to ensure quality of life for this patient (Oliveira, 2016 and Nascimento, 2015). Thus, there is a need to identify the preparation of caregivers regarding the gastro-patient who are dependent on care, as well as the most appropriate way to guide them about the care that should be provided to these patients in the home setting. This is because, when these patients who use gastrostomy, whether endoscopic or surgical, leave the hospital to continue their treatment at home, care is provided by their caregivers, triggering major changes in daily home habits. This can lead to a number of questions and fears about your ability to handle the situation. It is known that the experience of caring for a family member with a chronic condition is very difficult, the distress of lack of control can generate feelings of fear and anguish (Yamamoto, 2014). Based on this assumption, the present study has as its guiding question: What are the perceptions of caregivers of gastro-treated patients regarding their preparation for home care?

Thus, the study aimed to identify the perceptions of caregivers of gastro-treated patients regarding the preparation for home care.

MATERIALS AND METHODS

This is a qualitative, exploratory and descriptive study,5 carried out with caregivers who provided immediate attention after insertion of the Percutaneous Endoscopic Gastrostomy Probe in a private clinic, located next to a large Hospital in Santa Maria, Rio Grande. South, Brazil. The choice of this institution was due to the fact that it is a service specialized in endoscopic procedures, such as: High Digestive Endoscopy, Colonoscopy, Bronchoscopy, Endoscopic Percutaneous Endoscopic Gastrostomy, Intragastric Balloon, Esophageal Dilatation and Esophageal Prosthesis. The site has a health team consisting of nurses, nursing technicians, gastroenterologist, proctologist and thoracic surgeons. As inclusion criteria in the study, the participants considered that they provided immediate care to patients after PGS procedure, older than 18 years, who lived in the study municipality from January 1 to December 31, 2017. As exclusion criteria, considered caregivers of patients admitted to a Hospital Unit or Long-Term Institutions. During the study period, 22 patients underwent the procedure, a draw was performed and after that they contacted the caregivers responsible for the patients via telephone to invite and schedule the day and time for the interview. Considering that the data were collected until their saturation, the study population consisted of ten caregivers.

Data were collected from March to April 2018 through semi-structured interviews using a previously elaborated script, containing the following questions: Have you performed care in GEP? What types of GEP care were performed daily? How was the post discharge and if there were difficulties? What complications may have been identified? What guidelines were provided by health professionals? What if the caregiver had suggestions for patient care?

The interviews were held in a reserved place so as not to expose the research participants, lasting approximately 50 minutes each, being recorded with the consent of the participants and transcribed in full. All signed the Informed Consent Form in two ways, one way remaining with the researchers and another with the interviewees. The methodological framework adopted for the discussion of the results was Content Analysis6, formed by the chronological poles of pre-analysis, material exploration or coding and interpretation of the results obtained. The pre-analysis comprised the fluctuating reading of the answers to open questions, requiring direct and intense contact with the collected material, respecting some criteria of qualitative validity, such as exhaustiveness, exhausting the entire text, homogeneity, with clear separation. Among the themes to be worked on, exclusivity, since the same element could only be in one category, objectivity and adequacy or relevance, with adaptation to the objectives of the study. The exploration of the material was a process of reducing the text to meaningful words and expressions, performing the classification and aggregation of data, choosing the empirical categories responsible for specifying the theme. And, finally, the treatment of the obtained results was composed, proposing inferences and interpretations, interrelating them with the evidences on the subject. In order to preserve anonymity, the identification of participants was coded with the letter P, of Participant, followed by numbering 1 to 10, as follows: P1, P2, P3 [...] Regarding the ethical aspects, the recommendations contained in Resolution 466/12, of the National Health Council7, which presents the guidelines and regulatory norms for research involving human beings. This article derives from research registered at Plataforma Brasil and approved by the Ethics and Research Committee of the Federal University of Santa Maria, where it obtained an opinion. favorable under CAAE number 81271517.9.0000.5346.

RESULTS AND DISCUSSION

Between January and December 2017, 121 Percutaneous Endoscopic Gastrostomies were performed in patients at the institution where the research was performed. Of these, 76 were female (62.8%) and 45 male (37.2%), with varying ages. , where seven were younger than 20 years (4.1%), nine aged 21 to 60 years (7.4%), 30 aged 61 to 80 years (24.8%) and 77 patients aged over 81 years (63.7%). At the time of the active search for these patients it was found that 32 died, with death related to underlying disease (26.4%), 27 living in Geriatric Clinics (22.3%), 16 patients living in In other cities (13.2%), 7 patients had already removed the probe (5.8%), 8 patients were still hospitalized (6.6%), 9 patients could not be contacted (7.4%). Thus, we obtained a total of 22 patients who met all the inclusion criteria for the research (18.3%). Among the ten (10) participants of the research, six are caregivers of elderly without family ties with the patient and four are family members, with no experience in health. From the data analysis, two categories emerged, namely: Difficulties in home care after Percutaneous Endoscopic Gastrostomy and Follow-up after Percutaneous Endoscopic Gastrostomy.

Difficulties in home care after percutaneous endoscopic gastrostomy: Available as an Enteral Nutrition (EN) option since 1980, GEP has been used as a gold standard for prolonged enteral feeding in patients unable to swallow, and

the main advantages over others are the less invasive outpatient procedure8. Although GEP is considered a simple procedure, this study showed difficulties in patient care by family members or caregivers. Among the difficulties are the lack of knowledge and preparation by caregivers and family members to the new context of care: “I didn't know what it was, I had never seen it before, I knew when my husband put it, it was the first time I needed to take care of someone sick, one more relative.” (P1); “I am a caregiver, but the patients I took care of had the nose, this belly I met taking care of him, the nose just had to take care of him not to pull this belly now is more complicated.” (P2). It is known that the family, in addition to going through the changes caused by the process of falling ill of its relative, is still faced with diversified and often incomprehensible procedures that generate expectations and doubts and, consequently, fear and anxiety.9 According to one In a study on aging and increasing dependence, it was found that more than 90% of families did not receive home support to care for their families, making the main source of assistance for families the informal support system, for example, the caregiver (Oliveira, 2012). The research meets the results of the study, because linking the caregiver as a support to family members in the development of care at home after GEP, they become co-responsible for the patient. It was evident that the caregivers, who already had experience and who knew the PGS, had no difficulties: “I have already taken care of other elderly people who had this probe, and as work in the hospital there are also many patients who use it (GEP), for example. it already knew how to take care of it. ”(P10).

Currently, the feasibility of PGS performed at the outpatient clinic with a patient with good clinical conditions has been reported.2 In the study, patients underwent PGS on an outpatient basis, and no post-procedure hospitalization was indicated. Thus, the anesthetic recovery was in place and later released to the home. In these cases, caregivers were required to provide immediate post-procedure care:

[...] She came straight home from the clinic, so the probe had to stay open, to get a dark liquid that was inside, [...] there was a lot of blood on the first day too, soiling the bandage, the nurse told us that this was all normal, but we got scared [...] (P8)

[...] He came straight home with her [GEP], left a lot of liquid in a bag that had to be changed, and the bandage that the doctor put was all dirty with blood, did not know if that was normal or no, the first days were very complicated, I was very afraid of moving [...] (P1)

The outpatient approach is considered safe and efficient for various surgical and endoscopic procedures, among its advantages are the reduction in the waiting list for hospitalization, and providing more beds and professionals for the care of critically ill and complex patients.10 However, despite The authors mentioned above show the increase in outpatient GEP, the present study indicated difficulties in relation to immediate care, lack of preparation and adaptation of the family or caregiver to the patient. The caregivers of patients who underwent PGS and, due to complications, required hospitalization, reported that the first care was performed by the nursing staff because they were considered more complex. Being after the patient's discharge to his home the difficulties and doubts were different from those mentioned earlier: “I think the most annoying thing is to take care not to get too tight, to make the movement that the doctor teaches is something we cannot forget, and sometimes we wonder if it is too tight or too loose. ”(P7); “Some friends already took care of a patient with this tube, so they told me how to take care, but in practice it is much more complicated.” (P2). The difficulties reported by caregivers in these cases are related to the maintenance of the probe and the aseptic technique, which highlights the need for technical knowledge to perform correctly and safely. It is noteworthy that it does not mean that caregivers and family members who had their patients released to the post-GEP home without hospitalization did not show concerns and doubts regarding the technique either, but in a second moment, because for them the concern and priority difficulties were immediate care after the procedure. The research indicates caregivers' doubts regarding home care to gastro-treated patients, either due to lack of specific knowledge or orientation after patient release. Thus, the feelings of fear and insecurity are evident: "Seeing that rubber coming from her belly gave me an agony, I was very afraid of hurting when I had to move the probe." (P6); “At first I was a little unsure, I wasn't sure if I was doing it right or not, and I was afraid of it jumping out.” (P4); "I hardly moved the probe as the doctor had asked, because I was afraid." (P1); “It was a little difficult, because as I didn't know this probe, I was afraid to move it.” (P2) t is known that there are uncertainties in receiving the patient at home, because it is necessary to put into practice the guidelines provided by the nursing staff. It is up to the nursing team, with competence and technical-scientific ability, to act as a facilitator in guiding the caregiver, the bond established is essential for the process of training and autonomy of care (Mela, 2015).

The fear of the unknown and the inability with the techniques were associated with the concern that they were not taking care of the right way and interfering with the patient's comfort and quality of life: bed was no longer being easy for us, and when we had to start using these things [GEP]. ”(P1); “When I came home with her [patient], it gave me a certain dread, and now I was going to know how to take care of her, [...] we are not in health care, everything looks like a“ 7-headed animal ”. (P8).
Sometimes, the family starts to play the role of informal caregiver, needing more training and guidance, as they often have insufficient training or knowledge of the disease and care in the post-discharge process. Even if the family is welcoming, the care that the patient will need will not bring a healthy relationship, as the increase in their dependence will have implications for family life in everyday life (Mela, 2015). The responsibility for providing home support lies not only with the institution that performs the procedure, we have within the scope of the Unified Health System Health Care Networks (RAS), which are organizations of health services that seek to offer continuous and comprehensive care to population. The implementation of SAN in Brazil is still recent, which still runs into a truncated, bureaucratic and disjointed operation that does not take into account the needs of people within the system, which makes it slow and in many cases with unsatisfactory results (Arruda, 2015). In this sense, it is essential that the health team is aware of the support network of this patient, caregivers, family and the RAS to which this patient is part, in order to ensure continuity of care, avoid future complications and minimize difficulties faced. It is

known that in the process of home hospitalization, in the early days, there is a process of transfer of care by the nursing staff, which teaches the caregiver to perform different types of procedures that will need to be performed daily without the presence of professionals. The caregiver learns and reproduces, empowering the care process and decision making (Arruda, 2015). The home care notebook of the Ministry of Health, emphasizes that the GEP is included in the group of main procedures and care performed in home care, mentions the participation of the caregiver for the realization of home care, since the team will not be all the time. With the patient, family members / caregivers should be able to perform some less complex actions and procedures necessary to care for patients. For this to be possible, the team must develop trust and empower them (Costa, 2017). Thus, the study invites a reflection on the role that health services, in the figure of professionals, especially nurses, have in the construction of an integrated work between the different points of the RAS and the importance of health education of family members. and caregivers to ensure safe and quality home care.

Follow-up after percutaneous endoscopic gastrostomy: Healthcare professionals are accustomed to their daily routine and do not realize how strange and painful any new details can be for family members of patients. Guiding them about what will be done and explaining to their families the routines and techniques they will have to perform daily helps to overcome problems they experience (Freitas, 2015). Caregivers and family members reported having received post-procedure guidance from the institution's Nurse in detail and demonstrating on a probe template. However, written guidance and continuous follow-up after probe placement were not considered. Still, the interviewees' reports reveal that the verbal instructions given by the Nurse were poorly understood because it was a tense and distressing moment for the caregiver: “When I went to do it myself, it seemed that I had forgotten everything, it was very complicated”. (P2); “I was forced to be prepared, my daughter has only the min, [...] so I had to learn to do everything for her good [daughter], nothing is easy, at first I had many doubts, concerns.” (P9); “The nurse showed me the model of the probe he put in and what he should take care of [...] they could only give something in writing [...] so family members might read and understand a little more about the probe I think it would be interesting. ”(P3).

She [nurse] explained to me and my son and showed a probe just like my husband put it to show what was the part that was inside his belly. [...] they had to go perhaps to the homes of the people they put in to see if they are taking good care, or call to see if they have any doubts [...] (P1) Studies that relate nursing care to gastro-patients show that family members who get help from specialized professionals present less difficulties and doubts when providing home care.13 Written information, according to the Brazilian Ministry of Health, is one of the most important forms. of control and preparedness for new health situations.14 The need for information and written guidance is present in the reports: “Perhaps delivering something in writing would help a little, at home, alone sometimes doubts arise if we had where to resort to help a little.” (P6); “I just found it strange that we didn't give us anything written explaining it, but left us the phone if we needed anything.” (P8); “Maybe giving something in writing [...] because it may be that she forgets what she says, there is so much information, and more nervousness if she has something in writing we can read and remember.” (P2). The study found gaps in the preparation and follow-up of care, since the institution does not offer permanent and integrated post-discharge patient care. Thus, items such as the request for informational material where family members / caregivers could resort if they have any doubts about daily care and the request for home visits (DV), especially in the first days after the procedure, with recommendations for the care of the tube. and the clarification of the doubts were reported by the study participants: “Maybe they should have a follow up with patients who have gastro, call once in a while to see if they have any questions, if it's okay, I was often wondering if I was right or not. ”(P5); “Maybe a follow-up as soon as the probe is placed, calling or visiting to see if everything is OK could prevent further complications as well” (P6). The need for continuity of care, as a way of coping with the complexity of health problems, and the optimization of resources require a harmonious approach between hospital care and primary care. For the articulation between the different levels of care to occur, proper communication between service providers, health professionals and the strengthening of an integrated health model is indispensable (Mendes, 2017).

Conclusion

This study allowed identifying the perception of caregivers of gastro-patients to prepare for home care. There was a concern by caregivers about the proper care for these patients, as well as doubts about the techniques and daily handling of the probe, the question of not having received any written guidance about the care or having a permanent follow-up by the care team. Nursing of the institution was also reported. Thus, the study highlights weaknesses in the care provided to gastro-patients at home. It is noteworthy that patients depend on their caregivers for a better quality of life, thus, the knowledge, safety and ability of these caregivers to perform techniques properly, thus avoiding possible complications, is essential. Information regarding the procedure that the patient will perform, as well as the care that should be followed after this procedure is fundamental for a good prognosis of the patient. Thus, it is necessary to use strategies to provide appropriate and continuous guidance to these caregivers, where they can support and improve their knowledge and techniques regarding GEP. The RAS has a fundamental role in the care of patients at home, as well as in monitoring and ensuring comprehensive care. This research did not focus on the functionality of the RAS, however, it was observed that none of the participants cited the RAS, either for primary care or some other point, as an option to support home care. This suggests the construction of new studies that will work on this issue. There was a gap in the production of knowledge about the present theme, as there was a scarcity of national scientific papers addressing nursing care related to GEP. Thus, it is necessary to give visibility to this theme, to empower both professionals and caregivers, therefore, it is suggested to expand studies and research on the theme, in order to foster reflections and ensure the improvement of the quality of life of these patients.

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