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RESEARCH ARTICLE (ORIGINAL)

Family caregivers of people with a tracheostomy: (Dis)satisfaction with discharge planning

O familiar cuidador da pessoa ostomizada respiratória: (In)satisfação com a preparação do regresso a casa

El familiar cuidador de la persona con ostomía respiratoria: (In)satisfacción con la preparación para volver a casa

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Abstract

Background: People with a tracheostomy often experience physical and psychological changes, which can require a family member to become their caregiver. Discharge planning helps caregivers prepare for providing ongoing care at home.
Objective: To evaluate caregivers' satisfaction with discharge planning.
Methodology: This study employed a descriptive, quantitative methodology. A total of 30 family caregivers were surveyed, and data were gathered using the PREPARED instrument.
Results: We found that 53.93% of respondents were satisfied with the preparation for returning home. However, there was a low level of satisfaction, especially regarding information about medication, support structures, and self-care training.
Conclusion: Our study shows that a structured program of nursing interventions based on scientific evidence is important for meeting the specific needs of family caregivers. This can facilitate a healthy transition.

Keywords: nursing; patient satisfaction; caregivers; patient discharge; tracheostomy

Resumo

Enquadramento: A pessoa com ostomia respiratória sofre alterações físicas e psicológicas, podendo haver a necessidade de um familiar se tornar cuidador. O planeamento do regresso a casa permite capacitar o cuidador para a continuidade dos cuidados no domicílio.
Objetivo: Avaliar a satisfação dos cuidadores na preparação do regresso a casa.
Metodologia: Estudo descritivo, quantitativo. A amostra é constituída por 30 familiares cuidadores. A recolha de dados foi realizada através do instrumento PREPARED.
Resultados: Obteve-se um índice de satisfação sobre a preparação do regresso a casa de 53,93%. Verificou-se um nível de satisfação consideravelmente baixo, especialmente na prestação de informações sobre medicação, existência de estruturas de apoio e capacitação para o autocuidado.
Conclusão: Depreende-se do estudo a importância do desenvolvimento de um programa estruturado de intervenções de enfermagem, com base na evidência científica, que permita ir ao encontro das necessidades específicas dos familiares cuidadores, com a finalidade de facilitar a transição saudável.

Palavras-chave: enfermagem; satisfação do paciente; cuidadores; alta do paciente; traqueostomia

Resumen

Marco contextual: La persona con una ostomía respiratoria experimenta cambios físicos y psicológicos, y puede ser necesario que un familiar se convierta en cuidador. Planificar el regreso a casa permite al cuidador continuar con los cuidados en casa.
Objetivo: Evaluar la satisfacción de los cuidadores al prepararse para volver a casa.
Metodología: Estudio descriptivo y cuantitativo. La muestra estaba formada por 30 familiares cuidadores. Los datos se recogieron mediante el instrumento PREPARED.
Resultados: Se obtuvo un índice de satisfacción respecto a la preparación para volver a casa del 53,93%. Se registró un nivel de satisfacción considerablemente bajo, sobre todo en lo que respecta al suministro de información sobre la medicación, la existencia de estructuras de apoyo y la formación para el autocuidado.
Conclusión: El estudio muestra la importancia de desarrollar un programa estructurado de intervenciones de enfermería, basado en la evidencia científica, para satisfacer las necesidades específicas de los familiares cuidadores con el fin de facilitar una transición saludable.

Palabras clave: enfermería; satisfacción del paciente; cuidadores; alta del paciente; traqueostomía

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Introduction

People with a tracheostomy experience various physical and psychological changes, which may require a family member to become a caregiver. Discharge planning empowers the caregiver, facilitating the continuity of care at home and promoting a healthy transition to the role of informal caregiver (Stewart et al., 2022).

Nurses are instrumental in preparing the person with a tracheostomy and their caregiver for the return home. The goal is to help the person with an ostomy make a smooth transition to their new health condition, promoting and rebuilding their autonomy in the face of the dependency-generating event, namely the ostomy (Neiva et al., 2020).

From this perspective of continuity of care, and because there is a need to involve and support the caregiver in discharge planning, it seems like it would be important to investigate the satisfaction of the family caregivers of people with a tracheostomy with this process. This study is the result of an increasing need to prepare the caregiver of the person with an ostomy for their return home. Right now, discharge planning, within the context of the study, only includes teaching and showing procedures at the time of discharge. There is currently no structured and properly evaluated program in place.

The main objective of this study is to evaluate family caregivers' satisfaction with discharge planning.

We hope to contribute to a more comprehensive nursing intervention for the patient and family caregiver in hospital settings, thus promoting safety in the transition to home and improving the quality of life of people (patient/family).

Background

Having a tracheostomy can be challenging for numerous people with an ostomy and their families, who face daily new problems, fears, and impediments, with an impact on the individual's and family's cohesion, dynamics, and quality of life (Mendonça et al., 2017). Literature indicates that having a tracheostomy has a profound impact on the lives of people with an ostomy and their caregivers. This can lead to negative experiences related to stoma care, communication, well-being, quality of life, and social isolation (Neiva et al., 2020; Ptizer et al., 2022).

A study conducted by McCormick et al. (2015) in collaboration with the Global Tracheostomy Collaborative and the American Academy of Otolaryngology-Head and Neck Surgery examined the experiences of tracheostomy patients and their family caregivers after discharge. These experiences were reported as negative, stressful experiences, in which caregivers mentioned they had needs during this process, including the need for information on how to care for the patient and how to identify risk situations. These researchers found that only 50% of respondents indicated that they were *very prepared* at the time of hospital discharge, and 23% reported that they had received no training on how to act in an emergency.

In a separate study, Ptizer et al. (2022) sought to identify the challenges encountered by patients and their caregivers after returning home. Caregivers reported having experienced difficulties in stoma care and maintenance of the tracheostomy tube and having felt despair and fear when providing this type of care.

The authors posit that it is imperative to set up and improve educational programs with structured and personalized teaching methods. These should start in the preoperative phase and respond to the needs of the caregiver, including education, training, and evaluation, and use innovative strategies as resources allow. Such strategies include simulation on mannikins and print or digital leaflets (Ptizer et al., 2022; Ptizer et al., 2023). Neiva et al. (2020) agree that self-care training should start in the preoperative period, immediately after the decision on the surgical approach is made. Their study demonstrated that the preoperative consultation is an important tool to guide patients and caregivers, help them understand self-care, and build a therapeutic relationship with them.

McCormick et al. (2015) also suggest that standardizing education for emergencies and optimizing post-discharge support through coordination with community teams are measures to improve the quality of care.

Studies also show that effective discharge planning shortens the length of stay and reduces costs and readmissions. Ramírez et al. (2020) found that providing education on tracheotomy tube maintenance care resulted in fewer hospital readmissions due to complications.

From the patient and family caregiver's perspective, the transition from hospital to home can be a pivotal event of a hospital stay. It often leads to stressful situations for the person with a tracheostomy and their caregiver, as they have to deal with complex stoma care (Pitzer et al., 2022). It is imperative to view discharge planning as an essential part of care, with the main goal of supporting people with a tracheostomy in restoring autonomy (Santos, 2011).

The Directorate-General for Health (2017) recommends that health education for the person with a tracheostomy and/or their family caregiver should be conducted by an experienced nurse, start in the preoperative phase, be reinforced in the postoperative phase, and include a comprehensive discharge plan. Evaluating the patient's and family caregiver's satisfaction is crucial for assessing the efficacy of discharge planning.

Research question

What is the level of satisfaction among family caregivers with the discharge planning of people with a tracheostomy who are attending follow-up consultations at a hospital in central Portugal?

Methodology

This study employs a descriptive approach with a quantitative methodology. In order to enhance the quality of nursing care, it was deemed essential to assess the satisfaction levels of family caregivers with discharge planning. The target population was defined as informal caregivers of people with a tracheostomy who were attending follow-up consultations at a hospital. The following inclusion criteria were established: informal caregivers of patients of both genders, aged 18 or over who were able to read and write, had undergone a tracheostomy up to four years previously and signed the informed consent form. Informal caregivers of institutionalized patients were excluded from the study.

The sample was non-probabilistic and consisted of 30 informal caregivers of people with a tracheostomy. As the caregivers in this study are all family members of the patients, the Family caregiver concept was adopted. Data collection occurred between July and December 2019 using a form with two sections. The first section collected socio-demographic data and information about professionals involved in the care of the patient with a tracheostomy, the family context, and the care provided. The second section was the Portuguese version of the PREPARED instrument for caregivers, which was translated and validated for the Portuguese population by Ferreira, Mendes, Fernandes, and Ferreira (2011).

The PREPARED instrument groups items into process and outcome indicators. The process indicators include four domains: support structures, medication and management issues, concerns with community management, and control of circumstances. The outcome indicator consists of four questions.

To facilitate the analysis and processing of the data, a database was built using the SPSS software (version 24 of 2016). Subsequently, statistical tests were used for descriptive analysis, including measures of dispersion and central tendency, based on the type of variables. Bardin's (2014) content analysis method was used to process the qualitative data from the open-ended questions on the form. In terms of the conceptual and operational aspects, we followed the procedures laid out by Guerra (2014). Following the approval by the hospital's Ethics Committee and Board of Directors (number 040-19), data collection started. Participants were informed of the study and asked to read and sign a free and informed consent form, thereby confirming the information provided and their agreement to participate.

The authors who translated and validated the PREPARED questionnaire for the Portuguese population gave permission to use it in our study.

Results

The sample included 30 participants, whose sociodemographic, professional, and family backgrounds are shown in Table 1. The majority of participants were female (96.7%), aged between 27 and 70, with an average age of 52.1. Most family caregivers were married (80%), followed by divorced (3.3%) and single (16.7%). With regard to education, most participants have a low level of schooling. Specifically, 33.3% have completed primary education, and the same percentage has completed lower secondary education. Additionally, 8.3% have completed upper secondary education, while 16.7% have pursued higher education. As for their professional situation, 60% are employed, 23.3% are retired, 13.3% are housewives, and 3.3% are unemployed. The most common family caregiver is the spouse (66.6%), followed by the children (20.0%), and 83.3% of the caregivers live with the person who has the tracheostomy. Many of the respondents (36.6%) have previous experience as a caregiver. It was also noted that. in 50% of cases, the development of this caring role required the support of other family members and/or friends.

Table 1

Sociodemographic, professional, and family background characterization of the sample (n = 30)

Variables	***n***	**%**	**Summary statistics**
Age (years)			
≤3	2	6.7	Minimum = 27
31-40	2	6.7	Maximum = 70
41-50	9	30.0	Mean = 52.07
51-60	9	30.0	Median = 52.5
61-70	8	26.7	Standard deviation = 12.1
Total	**30**	**100.0**	
Gender			
Male	1	3.3	Mode = Female
Female	29	96.7	
Total	**30**	**100.0**	
Marital status			
Married	24	80	Mode = Married
Divorced	1	3.3	
Single	5	16.7	
Total	**30**	**100.0**	
Education level			
Literate	1	3.3	Mode = Primary education
Primary education	10	33.3	
Lower secondary education	10	33.3	
Upper secondary education	4	8.3	
Higher education	5	16.7	
Total	**30**	**100.0**	
Professional situation			
Employed	18	60	Mode = Employed
Retired	7	23.3	
Unemployed	1	3.3	
Housewife	4	13.3	
Total	**30**	**100.0**	
Cohabitation			
Yes	25	83.3	Mode = yes (Cohabitation)
No	5	16.7	
Total	**30**	**100.0**	
Previous experience as a caregiver			
Yes	11	36.7	Mode = no
No	19	63.3	
Total	**30**	**100.0**	
Help from others			
Yes	15	50	
No	15	50	Mode = no
Total	**30**	**100.0**	

Note. *n* = Sample; % = Percentage.

To analyze the study variables, we decided to take a process indicator approach, which includes the following domains: information on support structures, medication management, information on community management, and control of discharge circumstances.

In terms of the process indicators, we note that approximately 40.0% of caregivers reported a lack of information regarding support structures.

Regarding the process indicator Medication management, 26.7% of family caregivers indicated that the patient was not taking any medication. Conversely, 43.3% of respondents indicated that the information provided on this indicator was adequate, while 6.7% stated that no information was provided.

Overall, 63.3% of family caregivers reported that no information was provided during discharge planning on how to perform their usual tasks and care for the patient.

Regarding confidence in performing daily tasks at home, 46.7% of family caregivers reported confidence, although 50% reported uncertainty and 3.3% reported lack of confidence.

In terms of outcome indicators related to preparation for discharge from the hospital, 36.7% of family caregivers reported feeling completely confident about returning home, while 60.0% reported that they could have benefited from more preparation.

The overall satisfaction rate of family caregivers with discharge planning was 53.93%.

In response to the open-ended questions, five categories were defined, which were subdivided into subcategories. These are illustrated by coding units reported by family caregivers, as shown in Table 2.

Table 2

Schematic illustrating the categories and subcategories resulting from content analysis

Categories	Subcategories	Coding units
Teaching/information gap	Hygiene self-care	"They didn't teach to give a bath . . . I learned on my own" Q1
	Tracheostomy self-care	"Watching and listening was not enough, I should have practiced at the hospital . . ." Q21
	Procedure performance	"Only on discharge day, they taught me to tube feed . . ." Q11
	Equipment use	"He ended up in the emergency room because I mishandled the device." Q9
Factors facilitating the transition to caregiving	Previous experience as a caregiver	"I work with sick people . . . I had some experience, it was easy for me." Q6
	Learning technical procedures	"I felt confident because the nurses explained cannula care." Q26
	Access to health services	"I've seen a psychologist from the Portuguese Cancer League." Q6
	Strategies to cope with change	"It's been a while now and I've learned from experience . . . a new life, we have to adapt!" Q17
	Close family relationships	"I couldn't do it without my children!" Q28
	Low level of self-care dependence	"He has learned to do some things on his own, like cleaning the cannula . . . That has been helpful" Q19
	Therapeutic relationship	"Nurses are very helpful and always answer our questions and help us with anything, even on the phone." Q10
Factors hindering the transition to caregiving	Caregiver's health problems	"tendinitis that makes administration through the tube difficult." Q2
	Poor family support	"I am alone, I have no one to help me. . ." Q1
	Financial burden	"We should have more support, I had to be on leave to help him . . ." Q28
	(Un)preparedness of health professionals	"The health center staff could not show me how to do it . . . they are even afraid to touch it and tell you to go to the hospital." Q1
Family members' experiences of taking on the role of caregiver	Caregiver exhaustion	"I faced it all alone, I was burnt out!" Q26
	Caregiving uncertainty	"I was really scared because I didn't know how to handle the cannula." Q6
	Use of information sources	"I did some research on the internet search to better understand how to handle a cannula." Q30
Suggestions for improving caregiver preparation for returning home	Written and illustrated information	"Written information would be helpful, and with pictures to make it easier to understand." Q16
	Technical training to strengthen the teaching process	"I would like to suggest that caregivers receive some training, not just information . . ." Q9
	Creation of teaching protocols	"There could be ... an explanation (like a protocol) of post-discharge care. . ." Q3

Discussion

The results on the sociodemographic profile of family caregivers are consistent with those found in the literature. As we found in other studies, women are primarily responsible for caregiving. In fact, there is a significant prevalence of women taking on the role of primary caregivers (Mendonça et al., 2017; Ramírez et al., 2020). When it comes to age, we found that the age groups with the highest representation, at 30% each, are the 41-50 and 51-60 age groups. These figures match the findings in the study by Ramírez et al. (2020). As for the degree of kinship, we found that it was the spouse (66.6%), followed by daughters (20%). These results show that the family plays a pivotal role in caring for the person with an ostomy. The spouse and daughters are the most frequently identified family members responsible for care (Ramírez et al., 2020).

In most cases, the caregiver and the person with the ostomy live together (83.3%). Also, a study by Ramírez et al. (2020) demonstrated that the primary caregiver is typically a family member who is responsible for managing daily tasks and caring for the patient. With regard to education level, the majority had completed primary school, indicating a low level of schooling, in line with findings in other studies (Mendonça et al., 2017).

According to the data from the PREPARED questionnaire for evaluating the discharge planning processes, we found that, in the domain of information on support structures, 43.3% of the sample had not received any information. This is in line with the studies by Ferreira et al. (2011) and Pereira and Petronilho (2018), which identified gaps in how information on community services and equipment is shared.

As regards the domain of medication management, we found that the information provided was not comprehensive, with 23.3% of family caregivers reporting that the information received was insufficient. These results are similar to those from the study by Ferreira et al. (2011), which highlights the importance of providing accurate and safe guidance on medication regimes.

With regard to the domain of Information on community management, we also identified gaps in how information was shared on managing daily tasks and caring for the person with an ostomy. In this context, 30.0% of respondents indicated that they had not received any information on patient care. Participants emphasized a lack of teaching and information on hygiene self-care, tracheostomy self-care, procedure performance, and equipment use. These findings are in line with those found in the studies conducted by Castro et al. (2014) and Ptizer et al. (2022).

In the domain of Control of circumstances, 46.7% of participants reported feeling confident in performing daily tasks at home, while 50.0% indicated feeling insecure. These results are in line with existing literature. Family caregivers frequently have doubts and uncertainties about their relative's health status and the care they need to provide (McCormick et al., 2015; Ptizer et al., 2022).

Overall, caregivers are considerably unsatisfied with the information they receive on medication, support structures, and self-care training.

When it comes to understanding family caregivers' perceptions about discharge planning and transitioning into the role of caregiver, the respondents identified a lack of training and information as a key issue. These results are consistent with those reported in the studies conducted by Stewart et al. (2022) and Ptizer et al. (2022), which emphasize the dearth of information and training provided to family caregivers.

It is important to note that caring for a person with tracheostomy can be highly stressful, which requires the transmission of essential care information (Ptizer et al., 2023; Ramírez et al., 2020). This issue should be prioritized, given the significant challenges faced by family caregivers in managing tracheostomy care.

In the category of factors facilitating the transition, eight respondents identified learning technical procedures as a facilitating factor in caring for the family member at home. It enhanced caregivers' confidence and the patient's safety. Different researchers have also pointed out that nurses, as health professionals, can help people learn the new skills they need to take on this new role (McCormick et al., 2015; Ptizer et al., 2023; Ramírez et al., 2020).

When it comes to factors hindering the transition, the (un)preparedness of primary health professionals has been identified as a significant obstacle to the continuity of care. The absence of support from primary health care professionals has been found to compromise the quality of care provided at home, which often means going to the hospital to seek answers and solve problems.

In this context, Nakarada-Kordic et al. (2017) and Stewart et al. (2022) report a lack of communication between hospital and community teams, resulting in inconsistencies in the knowledge and skills of health professionals. Additionally, they indicate that the professional support provided to individuals with a tracheostomy and their families in the community following their transition to home is perceived as inadequate.

In the category of family members' experiences of taking on the role of caregiver, family caregivers reported feeling exhausted and insecure in performing care tasks, particularly those requiring technical procedures. These findings are consistent with those reported by Ptizer et al. (2022), who highlight that ineffective training can lead to significant physical and emotional strain for the caregiver.

Regarding suggestions for improving caregiver preparation for returning home, the respondents identified, among other possibilities, the creation of a teaching protocol. Several authors (Ptizer et al., 2023; Ramírez et al., 2020; Stewart et al., 2022) emphasize the significance of health professionals adopting a systematic protocol that implements effective interventions for a smooth return home. Neiva et al. (2020) also highlight the preoperative nursing consultation as a crucial resource for empowering both the patient and the caregiver.

The findings illustrate the significance of continuous support and monitoring of the patient and their caregiver.

In conclusion, this study is limited by the dearth of research on caregivers' perceptions of discharge planning among people with a tracheostomy. The limited number of participants also constrained the scope of data analysis, particularly the absence of statistical correlation tests. Furthermore, the lack of available literature on the subject precluded the transposition of results, which nonetheless align with the existing literature on the topic. Because some caregivers encountered difficulties in completing the data collection form, the researcher was required to complete it using the participants' answers. During the administration of the questionnaire, a climate of trust was established, and confidentiality and anonymity were ensured so that the participants' responses could be as authentic and insightful as possible. It is also noteworthy that the questionnaire was administered at a single point in time, which precludes the chronological separation and characterization of the implications of the various aspects studied, thereby increasing the likelihood of recall bias associated with the respondent's memory.

Conclusion

The findings of this study corroborate the existence of deficiencies in the preparation of family caregivers of people with a tracheostomy for their return home. The results illustrate the significance of continuous support and monitoring for both the patient and their caregiver. It is therefore evident that both the patient and their caregiver require the requisite knowledge and skills to enjoy an enhanced quality of life and well-being, particularly when they return home.

It is our contention that nurses should consider the needs and challenges of family caregivers to help them provide better informal care. If we anticipate their difficulties and act as health educators, we can equip them with the necessary skills to navigate this situation. To assist them in this transition, we need to adapt to this new role or, in the case of existing caregivers, adapt to the new demands that the new conditions of dependence require.

In order to respond to the research question, "What is the level of satisfaction among family caregivers with the discharge planning of people with a tracheostomy who are attending follow-up consultations at a hospital in central Portugal?," we obtained a satisfaction rate of 53.93%, which is below the desired level. Conversely, over half of the respondents indicated that they could have benefited from more comprehensive preparation to care for the patient at home, whereas only a third of the family caregivers reported feeling fully prepared.

The objective of this study, conducted in a clinical setting, is to elucidate the genuine perceptions of family caregivers, as recipients of nursing care, in order to enhance nurses' awareness of people's needs. This, in turn, will facilitate the implementation of strategic intervention plans to improve the quality of healthcare. To achieve these goals, it is essential to define and implement effective education and support programs for family caregivers to progressively promote their empowerment.

It is evident that there is a need to translate the potential findings of this study into a clinical context through the implementation of a structured plan for preparing the return home of people with a tracheostomy and their caregivers. This plan should be based on scientific evidence. The structured, evidence-based plan should be presented as a resource for decision-making by nurses, enabling them to meet the specific needs of caregivers.

To provide a more comprehensive understanding of the subject matter, it is recommended that the aforementioned study be replicated, with the implementation of the preparation plan as a prerequisite. Furthermore, the replication of the study using the PREPARED questionnaire in its version addressed to patients, health professionals, and community services is recommended to increase the relevance and scope of the aspects and focuses studied.

It bears noting that this study has confirmed the poor inter-institutional relationship between hospital and community teams, which jeopardizes the continuity of quality professional care. The provision of continuous training for nurses in primary health care is therefore essential to ensure an adequate and quality response to the needs of both patients and family caregivers.

Author contributions

Conceptualization: Anjos, V.
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Resources: Anjos, V.
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